

Back to Basics: Exploring gestural habits as cues for anticipating self-injurious episodes in a  
child with Autism and Deafness

by

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I dedicate this work to *family*.

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### ABSTRACT

This research project is a longitudinal qualitative case study. It contributes to an understanding of self-injurious behaviour (SIB) by inviting the reader through the narrative of the lived experience of a fifteen year old child-informant and the network of individuals in his life. The value and importance of a case-study is that it focuses on the authenticity of the experience of living with disability. Through the use of detailed field observations, interviews and photo documents, the study thoroughly explores three main areas: quality of movements, potential cues as pre-cursors to episodes of self-injury, and purposeful communication. The research begins with a review of literature on Autism, Deafness and Self-injury, formulates the research design and orientation of Physical Education, Phenomenology and Semiotics, and then systematically explores four distinct phases in the analytical process. The aim was to explore self-injurious episodes in the child informant in hopes to translate the meaning of the behaviour and potentially utilize this to provide more opportunities for adapted physical activity. The findings reveal distinct patterns of movement cues utilized for different purposes. The implications of the findings are self-injurious episodes in the child informant are preceded by distinct patterns of movement that are potentially communicative. Suggested future direction of the research is expanding the scope to other disabilities for which verbal communication is challenging, and standardizing the translating tools to assist in understanding the communication of movement.

**Keywords:** case study; lived experience; self-injurious behaviour (SIB); movement cues; Autism; Deafness; translating tool

## CHAPTER ONE: Introduction

*As I casually pull into the street a diagonal yellow sign reading DEAF CHILD AREA reminds me of the road I am travelling. This is not any road. This is not a typical street sign. It makes it real. I am not just conducting research. I am not just a Master's student. I am a stranger. I am trusted. I have been given a key. As I arrive, I am warmly welcomed into the home and eagerly position myself across the kitchen table where I will be for the next two years.*

### Background on the Research Path

It was not just one experience in my life that lead me to graduate work, but an intermingling of all my academic, extra-curricular, employment and volunteer experiences that lead me to my most significant academic accomplishment to date: my undergraduate thesis. It was within this applied academic experience that I had the opportunity to work with one specific child with Autism and Profound Deafness. I was intrigued, I was frightened, I was challenged and I knew then that there was nowhere else I wanted to be. During my experience, I had the opportunity to interact with the child in an adapted physical activity camp. It was the child's self-injurious occurrences that intrigued me the most. Other students described their responses to his behaviour as appalling, disturbed and shocked. To me it was anything but shocking, it was incredibly expressive. When the child repeatedly smashed his fist against his temple I was desperate to understand what he was saying. I wanted to know how, why and when the behaviour occurred.

In my educational pursuits as an undergraduate of Physical Education I had the opportunity to major in Disability Studies. Autism Spectrum Disorder has always drawn my attention but the specific interaction that I had at the adapted physical activity camp, was the most powerful interaction I had experienced to date. It influenced me in a way that other experiences did not. It drastically changed my perspective about the direction of my education. I realized I did not solely want to learn about Autism from others, or interact with individuals with Autism. I also wanted to personally find answers to some pressing questions about Autism's nature, specifically instances of self-injurious behaviour. I wanted to contribute novelty to the body of literature on self-injurious behaviour.

As I began to further explore the literature relating to self-injury and Autism it provided an inordinate amount of detail on: treatment options, behavioral functions, and the psychology of SIB (Iwata, Dorsey, Slifer, Bauman & Richman, 1994; Lovaas & Simmons, 1969; Richmond, 2008; Schroeder, Mulick & Rojahn, 1980) but I wanted more. It fascinated me. However, as I insistently searched I noticed studies had not even mentioned an observable movement repertoire in relation to self-injury. I thought, how could something seemingly "obvious" to a Physical Education graduate, not be considered in other observation-based research designs? I found myself drawn to one particular study that did utilize physiological response as a self-injury predictor (Barrera, Violo & Graver, 2007). In the three adults with developmental disabilities, and a history of severe self-injurious behaviour, heart rate was monitored, recorded and analyzed. The cardiac responses from the three participants were being analyzed in relation to the self-injurious episodes. The results of this study indicated there was a reliable and consistent pattern of heart rate before and after an episode of SIB (Barrera et al., 2007). Most specifically an increasing heart rate prior to an episode, and a decreasing heart rate post self-injurious episode (Barrera et al., 2007). The implications of these findings are two-fold. First of all, there is a



distinct physiological cue that precedes the self-injurious episode. Second of all, this cue can be reliably identified, and therefore potentially utilized as a predictor of future self-injury occurrence. If physical cues deep to the body's limbs could effectively predict occurrences of SIB, then physical cues superficial to the heart could too! Once I discovered this study, I knew that I too could embark on a research experience that would consider the observation of physical bodily cues and gestural habits in hopes to gain more insight into self-injurious behaviour.

I believe my research direction is especially important because it further expands on current research pertaining to observable behavioural cues in relation to self-injurious behaviours in children with Autism Spectrum Disorder (Barrera, Violo & Graver, 2007). I believe it is incredibly important to focus time and energy into seeking a thorough understanding of children's behavioural interactions within a physical education environment. Currently, the literature concerning how the 'disabled' body engages and interacts with physical activity is limited, and usually only exists in the form of a "special issue", as in the *Sociology of Sport Journal*, volume eighteen (Duncan, 2001). I wanted to help change this. I do not want children with Autism who engage in self-injurious behaviour to be denied an opportunity simply because self-injury is not fully understood when observed in a physical activity context. I feel it is my duty as a Physical Education graduate, to gain some knowledge about this specific context, and to share it with others. The bridge between what knowledge I currently had, and the knowledge I was seeking, was a particularly unique child. This child would teach me more than answers to my questions, but an extensive understanding of what it meant to live an experience.

### **Background on the Child-Informant**

**Social.** This young man is fifteen years old. He reaches gaze with the average adult of five feet and six inches. He is incredibly expressive with his face, hands and body. In my experience learning with and through him I learned that he is: independent, well-behaved, an attentive listener, intelligent and a gifted observer of body language. He enjoys looking up to and being mentored by a male, typically his older brother. He shares pizza when it is brought home from work, looks at family photo albums, swims, bowls, and hikes.

**Physical.** The child has a diagnosis of both Autism determined at the age of three years and one month by a Neuropsychologist, and Deafness which was diagnosed at thirteen months by a rehabilitation centre. The formal diagnosis of Deafness is profound bilateral sensorineural hearing loss; he expresses no physical response to any sound. This diagnosis exacerbates the difficulties of communication associated with a diagnosis of Autism. There is no history of either Autism or Deafness on either side of the child's family. He does not wear any protective gear such as gloves or a helmet to reduce the damage he self-inflicts. He also does not have any cochlear implants or assistive hearing devices.

**Cognitive.** Although a modified assent (permission of parent on behalf of the child) form was created on behalf of the child, the mother of the child informed me he was unable to comprehend the concept of signing his name and would be unable to read the form. The child's current level of comprehension is basic modifications to American Sign Language. He comprehends basic instruction such as time to eat, we have five more minutes, all done, clean up, and copy what I do. He is independent with his activities of daily living for instance, he politely cleans up after himself, changes himself and goes to the washroom himself.

### **Background on the Movement Camp**

Autism Spectrum Disorders Movement Camp (movement camp) is an environment where children and young adults with Autism Spectrum Disorders have the opportunity to engage in physical activity. Initially, interested students working towards credit must attend an intensive training session where they help create four different environments, each representing a distinctly different physical domain: body awareness/educational gymnastics, height and flight, game skills, and fine motor skills; flexibility and relaxation. Typically, the students do not associate any meaning to the equipment or activity spaces until they are educated and informed about the nature of movement that will take place in each setting. The training and application of movement concepts takes place once the students are within the corresponding room and have a base knowledge of Autism, common co-morbid disability conditions, and movement. Once formal training has successfully been completed volunteers are assigned pairings with the campers based on their suitability such as experience, background and demonstrated application of knowledge. Once a pairing has been made, the students have the opportunity to engage at each station they previously helped set-up and choose hypothetical activities based on their child's profile. Once camp officially begins, students are closely monitored and supervised while they facilitate movement with the individual they are paired with. Over the course of the two week camp, campers and students engage in all four activity space set-ups as well as swimming, outdoor activities, and four special events: go-karting, ropes course, Port Dalhousie (activity and beachfront), and the MacBain Centre (local community centre).

The camp's design is highly structured. Everything from the dim lighting to the number of campers in a room at a given time is planned and consequently applied. The objective of the camp is to utilize knowledge about the characteristics of Autism and design a space that will foster success. Each day a detailed visual schedule of each activity is displayed. A photograph of each activity and its corresponding physical space appears for every hour of the day. This is another aspect of camp that translates current literature on effective strategies to enhance physical opportunities for individuals with Autism, and applies it. For example, various spaces have foam mats on the floor that require individuals to walk with their feet flat on the floor to maintain balance. This strategy addresses the concern of *toe-walkers* (often times children with Autism walk only on their toes, avoiding placement of the heel on the ground). It is the responsibility of each student to program movement individualized to the individual they are paired with each day of the week. The success of this movement programming is fostered by a resource package administered during training sessions.

Despite the extensive amount of variables that are controlled in the environment an equal number of variables are uncontrollable, these include but are not limited to instances of: transitions from one space to another space, unpredictability in the schedule of the day, demands often physical demands such as ten sit-ups, other children's responses to the child-informant, and other children's behaviours at camp. This is the appeal and the difference of Movement Camp in comparison to typical programs - that the design of the environment is based upon specialized

knowledge about movement concepts specific to the population of Autism and yet fosters the unexpected, challenge of novel environments, adapted physical activity and exercise. Parents of the children who attend camp often describe how effective the camp is at addressing both physical and social needs, for instance as the mother of the child informant says:

Saturday October 23<sup>rd</sup>, 2010

*“Because it’s [movement camp] awesome. He’s [the child informant]...his physical movements...for muscle development, for focus because that’s always good, it helps with behaviours as well, if he’s physically active there’s no time...if he’s busy there’s less time for behaviours, it gives him something else to focus on, teaches him, broadens his world, there’s things that you can do besides being at home with mom and dad, it’s social exposure as well, I think that’s another important element of his development...boredom [relief from it]...social interaction” (Mother of child, Oct 23, 2010).*

Direct feedback from the individuals receiving the services is the most effective form of feedback. It provides the opportunity to continually design a unique and specialized program that caters specifically to the needs of the children who attend Autism Spectrum Disorder Movement Camp. In order to effectively explore movement programs for this population it is additionally necessary to address the usefulness of a movement framework.

### **Relevance of Movement Education Framework for Observation**

Movement theory directly relates to the objectives of this research project because it provides a medium from which the potential movement cues can be interpreted. Without a Physical Education framework, small almost non-observable differences to the untrained eye could potentially be overlooked and misinterpreted. Therefore, a movement framework based on the principles of Rudolf Laban is necessary to differentiate and emphasize the importance of particular movement cues and patterns, and especially in terms of *quality* of movement. In addition, movement theory will help develop a movement profile on the child-informant. The development of this profile will help inform the research about which movements are included in the child-informant’s general movement repertoire, is this movement repertoire the same when he engages in self-injury and if not what movement qualities are inherently different? It is important to further describe the framework of this research project in a detailed review of the literature.

## CHAPTER TWO: Literature Review

The objective of this review is to closely analyze the strategies and techniques that have currently been undertaken to assist in understanding and predicting patterns of physical movement as it relates to individuals with Autism. The initial overview of research will provide a collective portion of information that will help direct the aim of the study: to understand a specific case of self-injurious behaviour in a child with Autism.

### A Review of the Terms

**Autism.** Autism is a component of the umbrella term, Autism Spectrum Disorders, which encompasses a variation of disabilities that have similar behavioural expressions. These variations include: Childhood Disintegrative Disorder, Asperger's Syndrome, Rett's Syndrome, Pervasive Developmental Disorder, and Pervasive Developmental Disorder Otherwise Specified. Specifically, Autism is a developmental disability that commonly appears before the age of three (Nolen-Hoeksema, 2008). It is clinically diagnosed by a licensed professional such as psychologist, developmental pediatrician, or psychiatrist using The Diagnostic and Statistical Manual of Mental Disorders (Sears, Vest, Mohamed, Bailey, Ranson, & Piven, 1999; Lewis, & Bodfish, 1998). Within the Autism diagnosis there are three main categories of classification that must express abnormality or delay: "social interaction, communication, stereotyped or ritualistic behaviours and patterns of interest" (Lewis & Bodfish, 1998, p.80). A specific category of interest concerning repetitive behaviour in Autism is self-injury (Lewis, & Bodfish, 1998). There are a number of repetitive behaviours expressed in Autism for instance, hand flapping, object twirling, and the lining up of toys. Self-injury is simply one of the repetitive behaviour categories, and some other categories include echolalia, compulsions, obsessions, and rituals (Lewis, & Bodfish, 1998). It is essential to consider the co-morbidity of Autism and Deafness in the child informant to truly begin to understand the complex nature of his expressed behaviours and characteristics.

**Autism and Deafness.** Designing effective interventions and programming solely for Autism has its difficulties and when diagnosing the co-morbid condition of Deafness and Autism, the level of difficulty is further increased (June, Rapin & Tuchman, 1991). One pronounced difficulty being that both Autism and Deafness have challenges with communication (Vernon & Rhodes, 2009). Although the challenges in communication in both disorders are different, children with a diagnosis of both potentially have two times more difficulty communicating (Rosenhall, Nordin, Sandstrum, Ahlsen & Gillberg, 1999; Vernon & Rhodes, 2009). An additional challenge with the dual-diagnosis is that typically children diagnosed with Deafness are diagnosed with Autism at a later age. Although the prevalence of the co-morbidity is moderate, it is also likely undetected in a number of individuals. These delayed diagnoses consequently result in delayed interventions early in life that are designed to their unique needs and essential for their future success as participating members of the community (Beals, 2004; Guardino, 2008; Guralnick, 2011; Roper, Arnold & Monterio, 2003). Interventions such as Intense Behavioural Intervention, which would include other therapies and communicative interventions such as: the Picture Exchange Communication System (PECS), speech therapy, and sensory integration therapy would be delayed. However, there is a limited research and effective therapeutic services designed to address the characteristics of the disabilities when they are expressed together (June et al., 1991; Malandraki & Okalidou, 2007). June and colleagues (1991) found that: "Schools for the deaf, lacking experience with even

moderately autistic children, discharged deaf autistic children or refused to admit them because they found them impossible to teach" (p.1068). These children are now teenagers and young adults that have experienced inadequate services early in their life. The aforementioned variables stress the need for a comprehensive strategy that can be utilized in and out of the classroom to assist with understanding the communicative abilities of individuals with both Deafness and Autism. Ideally, this is where this case study research assists in the development of a comprehensive strategy. If a strategy template can be designed and effectively utilized for this child-informant, its reach can extend and be modified for any child who requires assistance in communication. In summary, the literature indicates there has been a limited amount of program availability, teacher education, and specialized knowledge in applied therapeutic services addressing the co-morbidity of Autism and Deafness. Once again, this suggests the importance of tools designed specifically to re-direct behaviours unique to the co-morbid condition and potentially enhance educational opportunities of children that have the dual diagnosis. In order to establish a more comprehensive understanding of all the characteristics of the child-informant it is also essential to review self-injury in detail.

**Self-injurious behaviour (SIB).** Before proceeding directly into a review of the strategies currently being used to predict patterns of movement, it is necessary to provide a detailed review of self-injurious behaviour. Self-injurious behaviour (SIB) is considered any harmful behaviour towards one-self that causes tissue damage (Barrera, Violo & Graver, 2007; Richman, 2008; Iwata, Dorsey, Slifer, Bauman & Richman, 1994). Most commonly this behaviour is observed in individuals with severe or profound developmental disability (Kahng et al., 2002). Potentially, this is indicative of the behaviour serving a communicative function when verbal communication is not commonly used. This physical tissue damage may include but is not limited to "scars, bruises, cuts, calluses and retinal detachment" (Kahng, Iwata & Lewin, 2002, p. 212). It continues to draw academic attention because of its complexities and idiosyncratic expressions. It can be expressed in numerous forms such as: hitting head on objects, hitting objects to head, hair pulling, self-scratching, self-pinching, self-biting and eye gouging (Fee & Matson, 1992; Kahng et al., 2002; Schroeder, Mulick & Rojahn, 1980). Additionally, it is important to note that its expression can vary in frequency, some individuals self-injure several times a week, some several times a day, and others several times an hour. The forms express themselves very differently in individuals and can range from mild (lighter, indirect movement quality) to severe (intense, direct movement quality and effort) (Schroeder, Mulick & Rojahn, 1980). It is also essential to explain the origins (as seen in Figure 1) of research on self-injury to assist in informing the future directions for individuals with Autism who engage in the repetitive movement. Self-injury has been explored and studied for a long period of time and continues to attract researchers' attention. It is important to note this paper will be exploring the ways in which a practitioner, a teacher or even a mother can predict self-injury occurrence specifically in persons with Autism.

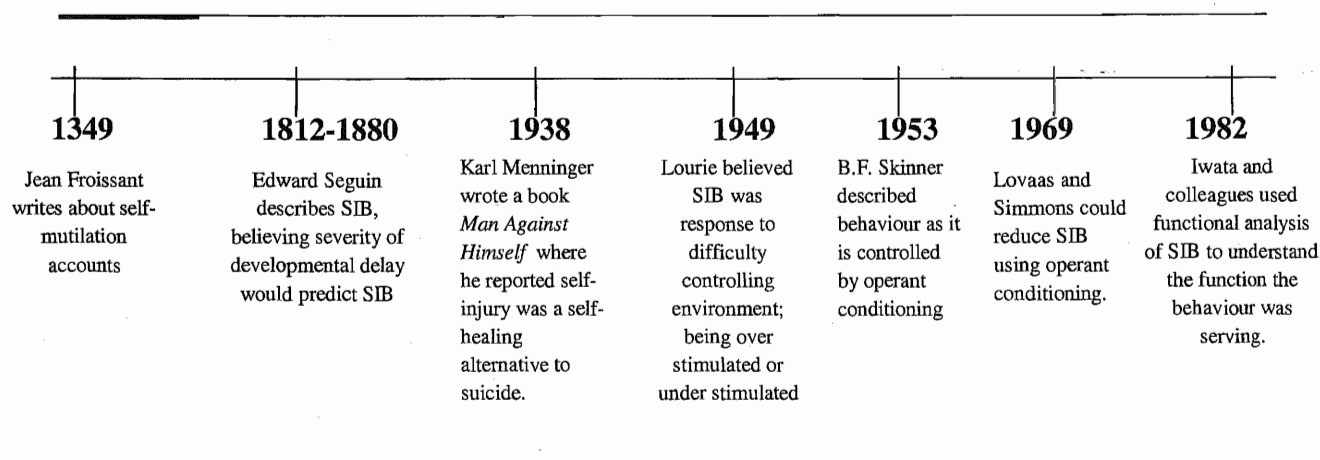


Figure 1. Snapshot Timeline. The origins of influential self-injurious behaviour research. (Muehlenkamp, 2005; Richman, 2008; Iwata et al., 1994).

Over the past six hundred years since the first documentation of self-injurious behaviour, there have been numerous questions pertaining to this particular phenomenon (Richman, 2008). Everything from what behaviours are considered self-injurious to why self-injury occurs, have been asked and consequently answered. One question remains uncertain: how can self-injurious behaviours in Autism be predicted before they even occur? Currently, the literature suggests that it is important to focus on prevention of self-injury (Richman, 2008; Kahng et al., 2002). Success has occurred with the use of antecedent analysis and functional analysis of self-injurious behaviour, for example, for self-injury associated with transitions, escape, and attention (Hanley, Iwata & McCord, 2003; McCord, Thomson & Iwata, 2001; Iwata, Dorsey, Slifer, Bauman & Richman, 1994). Despite numerous areas of success pertaining to self-injurious behaviour, a more detailed understanding remains necessary, for instance, behavioural researchers still express that “it is very discouraging to find that SIB continues to be a disorder that is very difficult to treat” (Kahng et al., 2002, p.220). There are particular cases that are very difficult to treat and this is where an innovative study such as the current one developing is most useful.

**Operational definition: Self-injurious behaviour.** Although essential to review the descriptions of self-injurious behaviour, it is also necessary to most accurately describe the self-injurious behaviour as it is specifically expressed by the child-informant. The child’s self-injurious behaviour is labeled *self-abusive behaviours* by his mother and it includes two distinct topographies head-banging (direct, intense force of head into a hard dense object such as metal door frame) and face punching (direct, intense force of closed fist into areas of the face such as orbital bone) (see Appendix A, Figure 1, p. 30). The face punching injury is produced by a closed fist, while the head-banging injury is produced by the slamming of the forehead against dense, hard objects such as doors, window frames, desks and floors. The injury is most frequently engaged in with hard, direct effort. Other than some observations of slapping the legs with an open palm, the injury is isolated to the vulnerable region of the head. Frequent direction of forceful injury mainly towards the region of the head is consistent with the literature (Barrera, Violo & Graver, 2007). The most common form of self-injury in the three participants studied by Barrera, Violo and Graver (2007) was also hand to head punches, closed fist and directed towards the cheek, temple and forehead. With a seemingly unlimited number of areas to direct

injury on one's body, it is observed that individuals engage in self-injury with minimal variation within themselves and across each other.

**Prediction.** Previous attempts to prevent self-injury occurrence have included some unethical techniques such as: electric shock, restraints, and lemon juice therapy (positive punishment). In addition, some effective techniques such as: time-out, over-correction, and manipulating the environment to induce self-injury while demonstrating experimental control, antecedent behaviour consequence recording charts, differential reinforcement of other behaviour, and differential reinforcement of alternative behaviour (Kahng et al., 2002; Iwata et al., 1994; Barrera, Violo & Graver, 2007). However abundant, the majority of these techniques still do not address the need to understand what the self-injurious behaviour is communicating and how it can potentially be predicted.

Research has presented numerous variables supporting why self-injury occurs, but the question remains if researchers can suggest why it occurs, can they suggest reliable ways how to predict its occurrence? It appears that despite understanding a broad spectrum of variables pertaining to SIB, there remains a need to continue to explore and understand the behaviour potentially as a form of deliberate communication.

Recently there have been some breakthroughs and research has revealed physiological cues that can potentially provide practitioners with predictive abilities. Once again, Barrera, Violo and Graver (2007) have specifically studied heart rate and its association with the function of SIB. They conducted a study with three adult participants (ages twenty-seven, forty-two and thirty-three) with Autism Spectrum Disorders. They had the participants interact with a technological development called the Lifeshirt. This Lifeshirt is simply a vest made of Lycra that is worn during the observation and experimental sessions of the study. The study simply manipulated the environment the participant was in: an attention condition (interacting with the adult), demand condition (requesting of an aversive task), control condition (engaging participant in activity such as walking) and alone condition (participant by themselves without objects). This procedure is called conducting a functional analysis of behaviour. Data is taken during each of the five conditions and then analyzed to determine the potential function of the behaviour. For instance, does the child self-injure at a higher rate during the demand condition when the therapist is requesting the child to answer a question or when the child is in the alone condition? All the conditions were utilized to determine the functions of the behaviour. In conjunction, the researchers also analyzed the physiological state during episodes of self-injury through electrocardiogram and heart rate readings from the Lifeshirt. Due to heart rate being easily observed and measured, it was the variable of choice. The results indicated that the function of SIB was escape, heart rate increased before an episode and decreased after an episode. These results are significant since they have shown that a physical pattern can be analyzed and potentially used to predict the occurrence of a self-injurious episode. The researchers declare the need to shift from an orientation of treatment and intervention to understanding the relationship between biology, the environment and the behaviour. This will help develop an understanding of the embodied experience of individuals with Autism who engage in self-injurious behaviour.

**Risks and benefits.** In order to justify why financial and personal investment is necessary for the study of self-injurious behaviour occurrence, it is crucial to present the influence self-injury has on those who engage in the behaviour. It has been documented that cases of self-injury can result in severe physical harm such as bruises to the head, swelling of the



face, and even damaged corneas (Barrera, Violo & Graver, 2007; Kahng et al., 2002; Richman, 2008). This evidence suggests this tissue damage can result in severe permanent damage and therefore from a risks-benefits perspective, needs to be carefully monitored. If researchers can reduce the physical harm induced by self-injurious bouts by redirection (understanding the act as a communicative function and responding to it as such), by even a small amount, the effects would be immeasurable.

In addition to the direct physical effects of self-injury, there are also a number of indirect effects. There may be physical side-effects of the medical treatments aimed at reducing SIB. Also, as a result of restraints, children can have shortened tendons (Kahng et al., 2002). In addition, the amount of social opportunities that a child can engage in can be greatly reduced by self-injurious behaviour (Greenspan & Weider, 1999). For instance, it may be dangerous and harmful to expose other children to another child's self-injury. Even other parents' perception of the dangerous and harmful elements of self-injury can socially isolate a child who engages in self-injurious behaviour. This could also greatly affect the amount of time that a child with Autism spends engaging in leisure activities due to the fact that most leisure activities are social in nature. One of the most debilitating effects self-injury has is on the quality of an individual's learning. If a child continuously engages in self-injurious acts, he or she is likely to be spending less time on skill development and more time on behaviour correction (Richman, 2008). This could greatly affect how much a child who self-injures learns on a daily basis. It is essential to teach new skills and facilitate learning, especially in individuals who have a pre-disposition to developmental delay. It is evident there are concrete examples of the effects self-injury may have on an individual's life. It has been determined that without intervention, the behaviour may become a life-long battle (Murphy, Hall, Oliver & Kissi-Debra, 1999). Therefore, as the current review of this literature suggests, self-injury is a severe area of concern especially for individuals with developmental disabilities (Symons, Sperry, Dropik & Bodfish, 2005).

It is important to establish a strong and effective predictive strategy first and foremost to ensure that self-injurious behaviour is not dominating the movement repertoire of the child who engages in it. From a physical education lens, it is essential to provide a child meaningful opportunities for physical expression that are the least harmful. Increasing these opportunities could then potentially increase the child's meta-awareness; his sense of self in the world, and his own understanding of his communicative abilities. All of these elements combined could also increase and improve his interactions with his peers.

The importance of designing a predictive strategy also has implications on the adults in the child's life, particularly the parents of the child and the service workers directly working with the child. A strategy could potentially help parents understand the child's non-verbal cues, provide a user-friendly strategy for observing the child, assist them in re-directing the child and enhance their sense of belongingness to the community by reducing the feelings of isolation (the only parents experiencing the occurrence). If the strategy is standardized and adopted by others, the parents could potentially feel more connected to the community of individuals supporting children with Autism who self-injure. In addition to the implications, this strategy could potentially have on both the child and adults in the child's life it also has large implications on the field of disability studies as a whole. Initially it could add to the description of the complex phenomenon. It could also potentially motivate further exploration of re-directive strategies,



encourage trans-disciplinary work and assist in the development of effective, individualized educational and movement programming.

## **Movement History**

### **Origins of Movement Theory**

In order to understand and accurately represent the movement of my child informant, it is necessary to review movement theory. The origins of a theoretical movement framework began with a man named Rudolf Laban. He was of European decent, born in 1879, in Hungary (Maletic, 1987). His influence and his theories had immense influence on education, dance and performance and politics across Europe, Britain and North America. He was a skilled teacher, choreographer and even founded his own dance company in 1910 (Maletic, 1987). The importance of his work to my research is expressed by a series of his objectives: that he "experimented with physical expression and spoken language" (Maletic, 1987, p. 8). He wanted to "...find a language that could be learned by all" (Maletic, 1987, p.8), and this language was a physical one; dance, both the gross motor and fine motor activity associated with the movement. His early objective was to "...unite the early most varied of dance talents on a common basis..." (Maletic, 1987, p.8). These early objectives have origins of inclusive movement practices and strategies for expanding the reach of meaningful physical expression. If movement is interpreted as a language and as a valid means of communication, studies aimed at understanding movement expressions will be far more frequent. The aim of Laban's study of movement is consistent with my aim as a researcher. Laban's aim was "...appreciation and practice of physical movement as a medium of expression for the individual, as a means of communication and as a discipline for the development of the individual as a member of the human community" (Maletic, 1987, p. 26). The qualities of most importance in this statement are that Laban believed movement was an expressive, purposeful, language that contributed to an individual's sense of self. Just as movement theory suggests, it is embodied experience and the facilitation of meaningful physical opportunities that are at the heart of my research. Therefore, the most important argument is that movement is a form of language. Laban formally developed his concept of movement into a 'language' that has four guiding principles: space, effort, relationships and body awareness. Each principle describes different qualities of movement as they relate to the environment they are expressed in. In its simplest form here is a brief description of each of these movement qualities: space describes the area the individual is moving in- is it large or small, open or closed? Effort is a description of the intensity behind the movement is it hard or soft, fast or slow? Relationships describes the interaction between the individual and other bodies or apparatuses such as a high beam. Body awareness describes how the individual feels themselves- does the individual know when they are contracting their abdominals, do they know if they are landing on their feet or their stomach onto a crash mat? Just as Laban's theory expressed, my aim as a research is to observe specific postural, gestural and physical properties of movement, in order to understand and illustrate the proposed child informant's movement as a physically spoken language (Maletic, 1987).

### **Current Applications of Laban's Movement Theory**

Although Laban's movement framework originates from the elements of dance, its application extends to various other forms of physical bodily expression such as: physical education, movement education and recreation (Schwartz, 1995). Over the past fifteen years, this theoretical movement application has integrated with technological advancement (Brownlow, Dixon & Radcliffe, 1997; Camurri, Lagerlof & Volpe, 2003; Camurri, Mazzarino & Volpe, 2004; Diaz-Castroverde, 2009). Even though progression and multi-disciplinary symbiosis has facilitated movement observation beyond Laban's time, it has also debilitated the successful use and application of movement observation in the general population. For instance, parents of children with developmental disabilities such as Autism may not have easy access to, knowledge of, or financial support for the current movement observation technologies. These technologies include but are not limited to: point-light display; where participants dressed in all black with reflectors on all major joints are video recorded and then biomechanically analyzed (Brownlow et al., 1997), expressive interfaces that use computer models and mathematical algorithms to analyze gestures and body movement (Camurri et al., 2003; Camurri et al., 2004), and gesture description format that also utilizes quantitative data to analyze physical movement (Diaz-Castroverde, 2009). Despite all of these approaches providing valuable insight into physical movement, they are mainly quantitative in nature. All of the current information on gestural and bodily cues is biomechanically and computer generated. What if someone does not possess this specialized knowledge? What are their options? It appears necessary to fill the gap between basic movement theory and advanced movement technology. There is a need to review the origins of Laban's movement framework, and suggest a technique that can be readily and easily applied by the network of people in for example, the proposed child informant's life.

### **Adapted Physical Activity**

Besides the obvious physiological benefits of physical activity (including but not limited to: increased muscular strength, increased muscular endurance, weight-loss, better proprioception, lower blood pressure) Goodwin and Watkinson (2000) further explored various other benefits directly from the perspective of eleven children with physical disabilities who were engaging in physical activity. These eleven children expressed that a positive experience of physical activity resulted in benefits such as "a sense of belonging, skillful participation and the sharing of beliefs" (Goodwin & Watkinson, 2000, p. 151). In addition to expressing comments about the benefits of activity, these children shared their negative experiences of participation in physical activity. Without appropriate, inclusive access to physical activity, Goodwin and Watkinson (2000) determined that these eleven children with physical disabilities felt "overshadowed, negative feelings, social isolation, restricted participation and a questioned competence" (p.151). These are all elements that no one should ever have to experience, especially when engaging in physical bodily expression. Although this specific study expresses the thoughts of only these eleven children, there are most certainly more, hundreds more children who are being denied the right to meaningful physical activity because their bodily expressions are misunderstood. It appears, by reviewing the literature that further research is still required to help understand why children with disabilities are being denied positive experiences in physical activity. Just as Connolly (2008) who works extensively with individuals with disabilities expresses: "...many children, youths and adults with ASD are unable to access meaningful, relevant physical activity programmes because of the complexities associated with their

behavioural, emotional and communicative idiosyncrasies" (p.234)". It appears obvious that this barrier to participation needs to change and a simple proposal to facilitate this change is to conduct more extensive research in this area of study that is easily accessible to those that need it the most, the children.

After a review of the databases on Brock University's website, it appears that my initial concerns have been reinforced. From a search of as early as 1964 to the present, the database search result of 'physical education' and 'disabilities' yielded a total of only 280 peer reviewed journal articles from a total of 7 journals (with Physical Education origins). What is even more disconcerting is that a refined search utilizing 'physical education' and 'autism' yielded even less (less than 3). How are parents, teachers, and youth who embody the experiences of Autism supposed to access meaningful movement expression, if physical activity and their bodily expression appear not to co-exist? It is my aim to help direct focus and attention in this field of study. I believe that by understanding my child informant's physical expression, I can help facilitate his participation in meaningful physical activity, potentially reduce excessive acts of self-injurious behaviour, and understand certain types of movement and physical activities as predictors of future behavioral episodes.

### **Teaching Students with Disabilities**

Given the apprehension many teachers have about teaching students with disabilities (Giangreco, Dennis, Cloninger, Edelman & Schattman, 1993; Campbell, Gilmore & Cuskelly, 2003; Hastings & Oakford, 2003), the prospect of teaching a child with Autism who self-injures is likely to generate a degree of trepidation in the mind of a classroom teacher. Might this apprehension contribute to the exclusion of children who self-injure from various educational contexts such as physical education? (Block & Rizzo, 1995; Hodge & Jansma, 2000; Lohrmann & Bambara, 2006). My aim as a researcher has been to gain an understanding of my child informant's self-injurious behaviour, so that he can be provided with more opportunities for participation in physical activity in school. If his movement is understood, then an individualized movement program can be implemented, and consequently his level of physical education participation will increase (Connolly, 2008).

## CHAPTER THREE: Research Design

### Purpose

The purpose of this research project was to explore pre-cursors that could potentially be used to predict episodes of self-injurious behavior. What if all documented acts of self-injury are not in fact self-injury but are communicative in nature and essentially warning signals that the likelihood of an occurrence of self-injury is high? If practitioners and individuals could use this information to design a simple tool that can assist in the re-direction of these self-injurious acts, the frequency and duration of self-injurious episodes could potentially be reduced. Consequently, educational opportunities would increase.

For the purposes of this research project, self-injurious behaviour must once again be operationally defined as it most accurately describes the behaviour of the child-informant. The child's self-injurious behaviour is labeled *self-abusive behaviours* by his mother and it includes two distinct topographies; head-banging and face punching (see Appendix A, Figure 1, p. 30). The behaviour is engaged in throughout several times in the day. Currently, there has been no documentation of distinct patterns of when the presences of each of the topographies are expressed. The face punching injury is produced by a closed fist, while the head-banging injury is produced by the slamming of the forehead against dense, hard objects such as doors, window frames, desks and floors. The injury is most frequently engaged in with hard, direct effort. Other than some observations of slapping the legs with an open palm, the injury is isolated to the vulnerable region of the head.

My research project is important to me because it has become me. I am invested in my research project, and thoroughly enjoy the process of being self-reflective and advocating my academic voice. This dedication and passion has and will continue to directly affect the outcomes of my research project. I do not perceive this as a hindrance to my research, but in actual fact as an asset. I have a keen eye for observing features of self-injurious behavior and an appreciation for developing rapport with the network of people in my child informant's life. These personal qualities have been influential to the development of my research orientation and approach.

### Research Orientation and Approach

The objective of my research is to understand a particular phenomenon of interest: self-injurious behaviour. This has consequently led me to approach my research with both a phenomenological and semiotic orientation. These two research orientations complement one another and focus on the meaning of experience (Patton, 2002).

### Phenomenology

I am most interested in the lived experience of my child-informant and the network of people in his life (Patton, 2002). Capturing the experience from these individuals, who everyday-live through the experience of self-injurious behavior is my overarching objective and that objective is heavily influenced by phenomenological characteristics (Patton, 2002). The specific questions I asked to understand the essence of the experience and explored how the participants perceive SIB, describe it, feel during it, judge it, remember it in past contexts, make sense of it and how they talk about it with others (Patton, 2002). The value in this approach is that the

detailed descriptions I collected are described in the words of my participants. Through this, I began to understand the language this specific network of individuals used, and was invited into their world. This consequently allowed me to authentically represent my child-informant in his world. It is important to note that although I qualitative work has a phenomenological perspective, the design of my case study is not phenomenological (Patton, 2002). I am able to utilize phenomenological characteristics to highlight the personal experience of the phenomenon of self-injury however I am not engaging in the particular methodological steps associated with this approach (Patton, 2002).

### **Semiotics**

I also want to understand the meaning my child-informant's movement has, and how it differs or relates in different contexts (Patton, 2002). I am proposing to interpret my child-informant's movement as a distinct form of communication that has identifiable patterns, signs and symbols (Patton, 2002). My underlying assumptions of my proposed questions are that my child informant's movement will have distinct rules and forms during different physical contexts, for instance his body will look differently when he is anxious compared to when he is bored (Patton, 2002). Again, this semiotic orientation blends well with phenomenology because it can help convey the essence of certain moments in my child-informant's lived experience (Patton, 2002). It will provide a means to present and describe particularly meaningful experiences (Patton, 2002). The phenomenological and semiotic orientation from which I am approaching my research and the specific research questions I am asking have informed all design feature decisions.

### **Research Questions**

The specific research questions examined in this process were:

- Can I, as the Principal Student Investigator, identify postural or gestural cues associated with SIB in the child informant's physical movement?
- Do these postural or gestural cues act as indicators of potential precursors for self-injurious behaviour in this child informant?
- Could the study of these physical cues provide development of a more comprehensive approach to redirecting self-injurious behaviour in this child informant?
- How can the child informant's physical movement be engaged as a form of communication?

The implicit assumptions underlying these research questions were:

- I, as the principal student investigator, will be able to successfully identify postural and gestural cues in the child informant's physical movement using Rudolf Laban's movement framework. Ideally, I would be able to identify cues in all of the child-informant's movement dating back to his infancy. Realistically, I will be able to identify cues in the movements I will directly observe over the course of the 4 to 6 month period.

- These postural and gestural cues will be precursory indicators of self-injurious behaviour in this child informant.
- These physical cues could provide helpful information on the self-injurious behaviour of the child informant to the network of people in the child informant's life.
- Based on keen observation, field notes, and video analysis of the child informant's movement, the physical movement will be identified as a form of non-verbal communication for the child informant.

### Research Design

Based on the answers I was seeking, this research project adopted the form of a single-subject longitudinal case study. The objectives of my research were consistent with and can be fulfilled by a case study. I required a method to collect "detailed, in-depth, extensive research that involved multiple sources of data" (Creswell, 2007, p. 73)-all elements which describe the qualitative nature of a case study. One particular author of previously developed case studies, Yin (2003), recommends that the multiple sources of data be: "interviews, documents, archival records, direct observations, participant-observations and physical artifacts" (Creswell, 2007, p. 75). I undertook four of the suggested methods to collect data: physical profile documents, interviews with the mother of the child informant, with student volunteers working with the child, and the child informant's service worker (if applicable), direct observations in a recreational setting and at home, and specific physical observations of the child informant. Based on my utilization of similar sources of data to Yin (2003) (cited Creswell, 2007), my research project possesses the essential elements of a case study.

### Participants

I utilized a single case to explore the issue of self-injury and physical expression. This case included a bounded network of people that contributed to the understanding of the phenomenon I investigated. These people included: one child informant, male, 15 years of age (at the outset of my research project); one guardian/mother of the child-informant; two student volunteers from the Movement Camp (one of which provided consent to but did not participate), and one service worker who was currently providing or had provided support to the child-informant in the last 12 months. It was this specific network of people that I interacted with, and sought answers from, in hopes to provide insight into understanding the child informant's self-injurious behaviour.

**The child-informant.** The child participant is a fifteen year old boy that I initially declared as having an endomorphic (wide build, fat hiding muscle gain) body type. However, after interaction alongside and with the child, I more accurately determined he has a mesomorphic body type (muscular). He has broad shoulders, and resembles a young football player. He has a sturdy, direct path of movement. He has strong core muscles and predominately uses quick sudden movements with his arms.

**History of the child-informant's self-injurious behaviour.** In order to gain a deeper understanding of the self-injurious episodes of the child it is necessary to explore the background history of his movement. What was the age of onset? This can help inform the research

questions. This historical timeline has been informed by the data sets, with a particular focus on the accounts of the mother of the child during her interviews.

[1]-infant; "I don't know...but it's funny from birth I knew something was up. Not self-abusive, just, having other child first, you do compare there was just different things that he did that were odd..."

[2]-age four; rocking with his hands behind his back, his head always up against a hard surface, he used to do this in his crib, head-banging, specific incident where smashed his head off the wall in the kitchen.

[3]-grade five or six (10 or 11 years old); face-punching began; "Umm, I think it kinda started by accident...", "...again now I can't really pinpoint when I noticed it, and I don't know what or can't recall what lead up to it, but it's a behavior he started, maybe he picked it up from school..."

[4]-age fifteen; "would be either him head-banging, banging his head against wall or surfaces, floor or wall, could be tv unit, the door frame, a chair, the counter, the fridge...oh ya windows, well the bus ones... French doors, oh the face punching oh and biting..." "...and again from that day on, it just kind of expanded...doors, doorframes, counters'.

To augment and further support the timeline of the behavior dating back to infancy, during the initial interview the service worker states "...but it's [SIB] something he's done his whole life from what I understand" (personal communication, Service Worker, November 18, p.30). The school personnel who are on the child's independent educational service plan are under impression the behaviour has always been part of the child's movement repertoire. Therefore, based heavily on the accounts of the mother and school personnel the child has been engaging in self-injurious behaviour for over ten years. It has progressively increased with intensity and frequency. It continues to dominate the movement repertoire of the child.

**The student volunteer.** The student volunteer was naturally selected as she was the volunteer paired with the child-informant at Movement Camp. She is a university student with a working knowledge of child development and physical education.

**The mother of the child.** The mother of the child was a key informant in this research project. She plays a very active role in her son's life and therefore offers the greatest amount of insight on his daily mannerisms and non-verbal body language. She drops him off every morning to Movement Camp, and often picks her son up in the evening. She is constantly opportunities to have her son to participate in physical activities. She is a firm believer and advocate of the benefits of Movement Camp.

**The service worker.** The service worker fulfilled the inclusion criteria of *worked directly with the child-informant for at least a year*. In fact, the service worker directly assisted the child-informant for over two years. The worker is fluent in American Sign Language.

## Measures

I used basic methods of data collection to measure my variables of interest, these being postural, gestural bodily cues. These included an interview guide to assist in conducting interviews with all willing participants. Also movement profile sheets helped organize my observations which were based on Rudolf Laban's four forms of movement (space, relationships, effort and body awareness). I collected detailed field notes to provide descriptions of the complexity of the physical behaviour being observed. To assist in tracking the descriptive detail of the body movements was a gestural coding system (see figure 2). Every documented episode of self-injury was transferred descriptively using this visual gestural coding system. The visuals were then analyzed as a continuing flow of movement when placed next to one another. It is important to note that I additionally had ethical clearance to video record to capture daily movement expressions while the child informant engaged in physical activity. However, due to the nature of the environment the child was observed in, it was more plausible and valuable to observe the movements live; as they were engaged in.

## Setting

The environment within which the child-informant's physical movement was observed was a Movement Camp held on Brock University's campus. This Movement Camp aimed to facilitate participation in meaningful physical activity. Activities at this camp included swimming, outdoor activities, educational gymnastics, and public community sites such as the park, petting zoo and race car track. Additionally, environments where recreational activity and leisurely physical activity took place, such as in the child informant's home, were an influential part of this research's setting. The duration and order of the observations depended on the accessibility of getting to each of the locations, the time my child informant spent at each of these locations, as well as the availability of the child's participation at these locations. Reiterating the initial literature review, there were limited opportunities to observe the child because he simply did not have access to the opportunities. I could not observe what was not present. However, what I slowly began to discover was the absence of opportunities to observe was data in and of itself.

## Procedures

Prior to any involvement of my participants, all consent forms were distributed in person by myself, the Principal Student Investigator, to the potential participants. I verbally described the research project and proceeded to allow the potential participants to independently read through the descriptions of the research project. Once completed any questions concerning my research were addressed. The consent form was then systematically placed into a binder designated solely to that participant and all future data provided by the participant.

Mid-week of the child-informant's participation in Movement Camp, the student volunteer participated in an interview. This interview was not video recorded, data was collected verbatim, and it was facilitated by the interview guide questions. Once the interview was



completed, the Principal Student Investigator began the transcription process. While the transcription process continued, the child informant completed his attendance at Movement Camp.

Beginning on the first day of Movement Camp, I, the Principal Student Investigator began to use a combination of keen observation, and field notes to analyze behavioural, postural and movement clues that may be displayed previous to a self-injurious occurrence. I made the decision to be an active participant in the movement camp setting, often engaging in conversation with other students and campers. This ensured that I blended well in the movement camp environment and that my behaviour was consistent with other students at camp. The collection of information included detailed observations of the child's physical movement using Rudolf Laban's framework of movement and field notes of the child's participation in camp activities. After the five days of Movement Camp, I continued to observe the child informant's movement across various adapted physical activity settings. The observational settings included leisurely activity within the home. These observations took place as they were made available, specifically on two separate days both scheduled dates for interviews with the child's mother. The order in which these observations took place again depended upon the accessibility of getting to each of the locations, the time my child informant spent at each of these locations, as well as the availability of the child's participation at these locations.

Once transcription of the initial interview was completed, a second follow-up session with the student volunteer took place. The objective of implementing this follow-up interview was to provide the student with the opportunity to confirm accuracy of the transcription and to make any necessary additions. Following the interviews with the student volunteer, interviews with the mother of the child and service worker were also conducted in the same systematic manner. An initial interview was conducted, following this, transcription occurred and finally a follow-up interview took place. It is important to note that the mother's follow-up interview as expected to be an hour in duration, and in fact was closer to three hours in duration. The fact that the interview extended far beyond the initial time expected is preliminary evidence the mother of the child had an incredible amount of insight to share and was a primary source for data collection.

### **Why A Case Study?**

The specific questions I sought answers to drove the specific research design my research adopted. As Creswell (2007) has indicated: "case study research has a long, distinguished history across many disciplines" (p.73). This detail was valuable to the outcome of my research, because the conclusions drawn were important to different disciplines and across various domains of the child informant's life. It was necessary to provide the most detailed, accurate account of this child's behaviour to assist in future physical interactions (Creswell, 2007). In addition, a case study design was chosen because it is essential to present data collected in a form that can be easily disseminated, shared and interpreted to those it is valuable to (the child, parents, teachers, volunteers and service workers of the child).

As a qualitative researcher, I "...seek to understand the world from the perspective..." (Merriam, 1995, p. 55) of my child informant. This allowed me to accurately represent and illustrate the "interpretation of my child informant's reality" (Merriam, 1995, p. 54). The information the case study design led me to was extensive details into the life of an individual

who has been traditionally misunderstood. Instead of aiming to correct or change behaviour, my aim was to observe details that might assist in the re-direction and formulation of less harmful and more meaningful bodily expression. The objective of a case study is to suggest new areas of research to be conducted (Creswell, 2007). With the support of the literature, and analysis of the findings, I intended to do just that: emphasize the importance of further exploring self-injurious behaviour.

**Limitations of a case study.** As in all qualitative research, the ability to generalize my research findings was not plausible (Creswell, 2007). Although, since I have specifically chosen to “explore a specific case within a bounded system” (child informant, Movement Camp, physical movement, and network of individuals important to the child’s life) (Creswell, 2007, p. 73), it is unnecessary to generalize to other situations. My objective was to gain a better understanding of a specific case, and to find answers that may assist this particular child and the case they are connected to. I specifically chose the study to be a single-site which also posed the challenge of less variation of information. Yet, it has been suggested by Creswell (2007) that “the study of more than one case dilutes the overall analysis; the more cases an individual studies, the less the depth in any single case” (p.76). Since the objective of qualitative research is not to generalize, but to seek an in-depth understanding, it was irrelevant to select more cases for the purpose of more variability of information (Creswell, 2007).

### Design Features

#### Sampling

The child and the network of individuals in his life were purposefully invited into my case study because they possess a very valuable web of information concerning self-injury (Patton, 2002). I successfully developed and continued to maintain strong rapport with the child informant, as well as his student volunteer workers, mother and service worker. This assisted me in gaining access into a very personal world of experience that would not be possible without qualitative investigation. I approached my case naturalistically. I only observed the child in physical activity contexts that he was already engaging in, not ones that were artificially constructed solely for purposes of conducting my research (Patton, 2002). The difference this feature contributes to my research is to the consistency of the child’s behaviour. By observing him naturalistically, I am observing behaviour that is typical of his everyday experience and not structured intentionally to fulfill my objectives as a researcher. In essence, this feature allowed me to observe authentic movement expressions. Early on in the research I made the decision to approach the case holistically, considering different domains and areas of life of the child informant (Patton, 2002). I specifically was provided access to observe the child in the home, and at a movement camp. This triangulation of settings has been useful to conceptualize and capture the authentic experience of my child-informant (Patton, 2002).

In addition to naturalistic inquiry, purposeful sampling and holistic perspective, I specifically integrated personal experience and engagement, empathetic neutrality and reflexivity features of qualitative inquiry into my research (Patton, 2002). All three of the aforementioned features were prominent features in my interviews and were an influential part of my analysis and my findings. My research journal was also a means to recognize which features were essential in my research project. I collected entries for my research journal throughout my data collection.

## Data Collection

**Document analysis.** I decided to challenge myself both as a learner and as a researcher by undertaking a photo document analysis. This form of document analysis was novel to me, and I believe enhanced my ability to critically analyze and inform my research questions. This particular form of document was well suited to my research questions because by nature, photographs capture physical elements of the environment. In addition, the benefits of deciding to be a participant-observer during movement camp observations are that I already had direct access to the data set; the photographs. My decision to take an active role allowed me to gain access with little to no challenges.

In addition to the photo analysis, I was directed to another form of document that enhanced my research inquiry. I analyzed some behavioral data that the mother of the child-informant previously took for an entirely different inquiry. This portion of the second data set were information rich because it was directly observed and collected by one of the key-informants in the child's life: his mother. Although my initial place of inquiry was to explore observations made directly by individuals in the child's life, I was also able to have valuable insight in the form of observations.

**Fieldwork Observations.** *There's a chaotic murmur and the flicker of bodies lights up the dim lit open space. Suddenly it is quiet to my ears and it becomes loud in my eyes. What I see begins to speak.* The field I conducted my observations in was dynamic, fast-paced, and movement goal-oriented. It was an Autism Movement Camp designed specifically to facilitate physical activity opportunities, and expand the movement repertoire of an otherwise inactive population of children and young adults. Again, since I had previously participated in this field, I was technically an insider who was able to transform into an outsider. I was able to remain an insider while observing the environment from an entirely new perspective. I had the opportunity to observe familiar activities, people and actions, and analyze them as though they were unfamiliar research territory (Patton, 2002).

I decided to fully disclose myself as a researcher to everyone in the space: students, volunteers and parents. This helped facilitate me in taking meaningful and uninterrupted field notes. Although, my narrow focus and short period of available time (4 to 6 months) have been main contributors to some research challenges, I have decided to observe my child-informant in physical activities that naturally take place in his life. Interestingly, an emerging pattern seems to be that this child has little to no access to physical activity, recreation or leisure, and therefore I have little to no fieldwork data collected. Despite initially appearing as a limitation to my study, I have interpreted the absence of opportunity as valuable data in and of itself (Patton, 2002). The fact that there is no opportunity for the child has emerged into a valuable theme that has become an important avenue of exploration.

Some additional challenges that arose during this qualitative experience were overlooking details that had become familiar to me as an insider. I overlooked some valuable context-building observations simply because of the nature of my previous role in the specific

environment. I had to step outside of myself and my previous ideological assumptions to successfully maintain rich, detailed observations. This research has and continues to change me (Patton, 2002). Change me as a student. Change me as a researcher. Change me as a life-long learner.

**Interviews.** As I learned more and further developed an understanding of my child informant's self-injurious episodes I was naturally driven to ask more questions. The closer I came to the lived experience of the phenomenon, the more I became overwhelmed with the desire to gain more insight and detail. To seek answers to these pressing questions, I designed interview guides (see appendix Figure 3). The style of interview was proven to be useful and appropriate for my inquiry because in addition to collecting information-rich data to questions, I personally answered as I became a more skilled interviewer, I had the opportunity to add more insightful and discussion-provoking questions.

The benefits of utilizing an interview guide (see appendix Figure 4) are that it provides flexibility during the interview, questions that emerge can be asked. In comparison, an alternative design may have standardized questions that are the only questions that can and need to be asked to all participants. This design feature provided contributed to the qualitative inquiry into the lived experience of self-injurious behaviour. The basic guideline provided a framework of issues that were relevant to explore, but did not limit the natural course of seeking answers to complex phenomenon. Once the data collection procedures had been completed, I began my analysis.

### **Data Analysis**

The data collected was analyzed to find specific themes and patterns that would provide more insight into the nature of this child informant's self-injurious behaviour. The analysis was broken into four distinct stages. The first stage was designated to analyze all three data sets utilizing key words, phrases, objects and happenings. The objective being to find the child's: dominances in movement, gaps in movement, sequences of behavior and patterns of posture and gesture. The second stage of analysis was distilling the initial set of findings into coherent patterns within and across data sets. In the third stage of analysis I then utilized reduction strategies of strong words, idiomatic expressions and repeating phrases. This stage of analysis helped me confirm or disconfirm the details in stage one. The last stage of analysis was a consolidating comparative analysis across all previous stages. I sought answers from the current body of literature on the themes and patterns that developed through stages one through three. In summary, analysis phases one through three were all inductive and indigenous in nature. The observed patterns were developed from the three data sets, shifting from specific to general and were specifically unique to this particular child. The final phase of analysis was deductive in nature and answers were sought from the body of literature on self-injury. The stages of data analysis were appropriate for my research because they specifically relate back to the questions I am asking. The research questions inform the method of data collection, which inform the types of analysis and lead to the findings.

Table 1

*The Phases of Analysis*

<i>Phase</i>	<i>Data Set A</i>	<i>Data Set B</i>	<i>Data Set C</i>
Phase I	Interviews  a) Within case-keywords b) Cross case	Observations  a) Generic person rubric of location of each episode of injury b) Written chart of frequency and duration of each self-injurious episode c) Daily movement profiles	Images  a) Body, space, time & relationships b) Assumptions & attributions c) Context
Phase II	A  Patterns	B  Patterns	C  Patterns
Phase III	Cross set comparison and integration		
Phase IV	Comparing and confirming literature typologies		

**Trustworthiness and Soundness**

Through out the research process I have implemented features into my project to ensure the trustworthiness of my data. I have utilized follow-up interviews whereby the participant member checks the transcribed interview. Once I had conducted the initial interview I set up a

follow-up interview. In the follow-up I provide a printed copy of the transcribed interview and the participant reads through it for accuracy and to ensure the quotations represented their voice. This has been useful for easing the participants into the analysis stage of my research project; there are no surprises. This also helped provide trustworthiness for the authenticity of participant voice.

In addition, for interviews that I have received consent from participants, I have utilized audio-recording and transcribed verbatim. This too helped build the trustworthiness of my data. Verbatim transcription is the closest to the raw data and has the least amount of interference in the early stages (Patton, 2002).

I have utilized triangulation in my literature review, my data collection and in my analysis (Patton, 2002). The application and inclusion of all three of these forms of data result in robust qualitative research. By including document analysis, observations and interviews, information can be confirmed, re-confirmed and disconfirmed. The value in this is that any claims that are made have been triangulated; approached three different ways. The proposed results of this method of qualitative inquiry are the themes and patterns that emerge will be in-depth, detailed and descriptive.

I have also been keeping a detailed research journal throughout the research process. This journal has been effective at facilitating reflective thought and it provides another avenue to explore my decision-making process. If concerns or questions about the trustworthiness of my data arise, I can consult my research journal. The research journal also acts as a source to check for biases.

To ensure my data is both trustworthy and sound I disclosed relevant biases. These biases would naturally be disclosed as they are suitable for instance; biases concerning my methods of data collection were initially outlined in the beginning of my data collection section. While biases concerning my analysis, were outlined in the beginning portion of my analysis section. In order to further explore trustworthiness of my data it is necessary to discuss the relation of my design features to my orientation.

## CHAPTER FOUR: Research Findings

Since an interview guide was utilized and different questions for each participant emerged during the process, findings have been summarized and presented holistically. The first data set is organized by patterns found within the participants' interviews. The second set is a summary of patterns explored across all three participants. Following the presentation of the most prominent patterns and findings a contextualization of the information is made. The relationship each set of findings have to the initial research questions asked is described. In addition, in italics I have included excerpts from my research journal. I have documentation of myself as a researcher and how this helped inform my decisions made throughout the research process.

### Within

This section describes patterns that were found separately within each interview. The selection is based on powerful statements, words, objects and points of interest that began to lay foundation for the answers to my research questions. The data is presented in chronological order.

**Student volunteer.** The student volunteer was purposefully recruited, as she was the student volunteer paired to the child-informant at Movement Camp at the time of data collection. She was an undergraduate student with a background in child and youth development in addition to physical education. She attended movement camp training and participated in movement camp for the duration of the week (5 days total). On a daily basis the student volunteer observed the child's behavior and movement from 9 am to 4 pm she states: "98% of the time I'm with him, watching" (Student Volunteer Sept 1, 2010). Although in comparison to the other participants she spent a shorter duration of longitudinal time observing him, a short condensed period of time was specifically designated to observing and using these observations to effectively program movement activities for him. Hence, why this participant was purposefully selected- she had access to detailed movement observations, naturally coherent with the objectives of my research questions. Her opinion is greatly valued because her observations are also informed by her Physical Education background. She has a greater potential to have a keen eye for observing the potential movement cues that are being expressed. In addition, her observations are important because they because at the outset then begin to directly answer the pressing research question: *how can the child's movement be engaged in as a form of communication?* The observations of the child's movement have been made in a recreational setting. The patterns found in her set of interviews that were influential in supporting the research questions are presented (refer to table 2).

Table 2

*Student Volunteer's Patterns Within Sample*

<b>Words</b>	<b>Powerful phrases</b>	<b>Objects/happenings</b>	<b>Points of interest</b>
School	"...because I don't think he wants to hurt himself"	"Also I noticed today [at Marineland] people looked at him like some savage beast just released from a cage, people just see that, they don't know he's quiet, they jump to conclusions about him"	<i>Repetitive behaviour the child engages in:</i> "He slaps his leg a lot, sometimes by himself he grunts, I know then that he's uneasy, and when he starts to get angry, the way he moves his head and clamps down on his jaw, his eyes widen; widen and focus and when he normally he never makes eye contact"
Hurt	"He is well behaved, very well behaved, he takes direction very well, he listens to you, he's not a horrible child, his [SIB] is overpowering...overbearing to all his other great characteristics"	Emotional response to the behaviour: "...because no one wants to see a child hitting themselves"	<i>Public's knowledge of repetitive behaviour:</i> "Not well at all, because I wouldn't have understood it [SIB] and I volunteer at a school with children with Learning Disabilities, I've worked with a child with Autism at this school, I'm there at least twice a week all year since October 2009. It's not like I haven't been around children with disabilities"
Frustratedx14			<i>How behaviour affects child's life:</i> "He needs to integrate with other kids, also his episodes are usually on himself, if his EA's and teachers are scared and think he's dangerous this will affect his education"

The important characteristics that the student volunteer's interviews address are misconceptions about children who engage in self-injurious behavior, fear of and frustration with SIB, and the function of the behaviour. These elements begin to address the following questions:



how can the child informant's physical movement be engaged as a form of communication, and could the study of these physical cues provide development of a more comprehensive approach to redirecting self-injurious behaviour in this child informant? If the student volunteer believes the child does not want to hurt himself this is a strong indication that at least one other individual believes he is communicating through his self-injurious behaviour. She also describes he likely is expressing his frustration through this particular means. Both descriptions are preliminary evidence that he is relying on his behaviour as a means of communicating. They also emphasize the need to re-direct this communication since it is necessary to express an emotion but additionally dangerous to his well-being. The first step to re-directing communication is to first understand what it means. The aim of this stage of analysis is to lay a foundation from which a comprehension of the complexities of the child-informant's behaviour can be developed.

*September 22<sup>nd</sup>, 2010:*

*The physical position the participant began in was seated upright, and then as the interview progressed the participant moved onto their stomach, their feet in the air, I believe this physical expression was an indicator of comfort, and ease during the interview process.*

This excerpt from my research journal showcases my ability to observe and notice the body. I was naturally picking up body cues the student volunteer was expressing, in hopes to maintain the flow and comfort of my first interview. The quality of the student's answers could have been influenced by her comfort level and therefore it was an important aspect to consider during the process.

**Mother of the child.** The second interview I conducted was with the mother of the child-informant. She has spent her whole life dedicated to her son. She spends all day with the child she states that on a daily basis she spends: "...all the time. Probably too much" with her son. She therefore has the most robust set of observational descriptions based on number of years of observations. The observations of the child's movement have been a variety of settings, most specifically in the home. The patterns that were of most importance in this data set can be seen in the following table (see table 3).

Table 3

*Mother of the Child's Patterns Within Sample*

<b>Words</b>	<b>Powerful phrases</b>	<b>Objects/happenings</b>	<b>Points of interest</b>
-fix it x3	-mom describes/compares saying "...it's like working on a machine or a car you just get to know it, like a mother's intuition, I can't explain" -again makes a reference to machine like qualities: "It	-child smashes his head through the school bus window: "I think you heard...they kicked him off the bus and I had to drive him for three weeks, and then they called the Corrections Canada to find out how high-risk criminals are transported they made him into this...he was aggressive and like you know, aggressive with intent not understanding what autism is...their	<i>How well do you think people understand SIB: "I guess from what I see, most people would look at it [SIB] and be horrified"</i>

	<p>would be great if I could fix it. I mean how do I fix it..."</p> <p>-“I don’t know if they assume it’s bad parenting or you should fix it-make it better..."</p> <p>-“perhaps if he can tell me <i>Mom I hurt I don’t have to hit myself to do that, I can sign that and she will understand, I’m not feeling well, something at school upset me...</i>”</p>	<p>ignorance”</p>	
	<p>-she describes the parents of children with Autism as “war veterans don’t really talk about it, you can share stories with others living it”</p>		<p>-reference to her parenting and remnants of refrigerator mom; “Typically people would not see [SIB]...my thoughts are that most people would not understand...well I can tell by their faces I mean oh my god, I mean the looks, I mean I’ve seen it all...what horrible parenting...you know...what is that child doing...the past few years have been so busy you can’t do everything. I used to have him skating...there are three other people in the family we all have our needs...”; some attributing to her own actions with use of switch in preposition from you to <i>I</i></p>
	<p>-“the child gets 98.8% of everything, 99.9%...”</p>		

The most important point to note is the re-occurring pattern of lack of knowledge of self-injurious behaviour. Considering the frequency the child engages in the behaviour (several times

a day), the amount of perceived knowledge of the individuals interacting with the child on a daily basis is disconcerting. This again addresses the question: could the study of these physical cues provide development of a more comprehensive approach to redirecting self-injurious behaviour in this child informant and the need for the development of a comprehensive tool.

*October 23<sup>rd</sup>, 2010:*

*I believe I am becoming a more skilled listener, and asking for clarification. I was able to write down responses, observe body language, provide feedback and engage in conversation with mom.*

It is interesting for me to continue reflecting on my own experiences as a researcher as it adds some depth and clarity to the research process. As I progressed through the research process I too was able to grow and learn. The process has been both fascinating and exhausting.

**Service worker.** The service worker is a school personnel who has worked one on one with the child in the school setting. They have known the child in this specific capacity for a two year period. On a daily basis the amount of time this individual spends observing the child-informant's movement is as she says: "All day...when he gets off the bus too when I put him back on the bus in the afternoon, so...say ten to 9 to 3 o'clock ish" (Service Worker November 18, 2010). The observations have been made in the school setting. The patterns found in the service worker's interviews are presented in the following table (see table 4).

Table 4

*Service Worker's Patterns Within Sample*

<i>Words</i>	<i>Powerful phrases</i>	<i>Objects/happenings</i>	<i>Points of interest</i>
-beats -beat -beating	-massive hitting	-“we have one that screeches and screams and screams and screams...”	-emphasizes the point of injury is usually the left side (pg.10)
-cheeks		-“...he'll just bruise those cheeks because he hits them so hard...” (pg.13)	-“again, the left (uses actions) comes up and he hits his cheek bone with the...the bottom part of his hand right here (shows the bottom of the palm), he always has a closed fist”

The most prominent emphasis in this data set was on the descriptions of the act of the self-injury itself. Interestingly suggested patterns that have been considered are the child's favouring of the left side. This information can either be confirmed or disconfirmed by the other data sets of field notes, and photo documents.

*November 23<sup>rd</sup>, 2010:*

*My first level of analysis that occurred with the verbatim transcribing process was the number of times the phrase “you know”; I know for some reason that this will be of importance and I believe it has to do with this notion of expert, who possesses knowledge and the power dynamic between interviewer and interviewee. It could possibly be out of habit, but my initial interpretation of it, was that the participant was possibly de-valuing what they were saying out of insecurity that they are not the expert and looking for my (as an ‘expert’) confirmation.*

This is evidence of a developing theme that will also be further analyzed in the across data set stage of analysis. It is important to reflect on because it again emphasizes this notion of knowledge, misconceptions and what expert opinion exists on this area of study: self-injurious bodily cues.

### Across

This data set is a summary of the patterns found across all three participants’ interviews. The pattern category has been listed on the far left column while each participant’s answer appears in the columns following it. The *italicized* details (see table 5) indicate areas that will be further interrogated and a thorough discussion will be informed by these specific categories.

Table 5

#### *Patterns Across Data Sets*

<i>Pattern Category</i>	<i>Student volunteer</i>	<i>Mother of child</i>	<i>Service worker</i>
Most common emotion	-Scared -Frustrated	-Frustrating for herself -Child frustrated	-child’s frustration -others are scared
<i>Categorized under the social section of the interview under how it affects the child’s life</i>	<i>-“I knew of cutters”...</i>		<i>-“...they’re doing it because they haave to do it you know, it’s almost like that need-it’s almost like a cutter...” -“...right like they have that need they have to cut...that’s a self-abusive behaviour”</i>
How would you describe the child’s movement	-“Lazy.”	-“sluggish, you can put a bomb under him and he wouldn’t move vs. he’s quick though, but then he can have purpose”	-“plain, mellow, plods vs. quick, very quick, blink of, the speed is...there”
<i>Place/site of the SIB</i>	<i>-jaw -forehead -face -closed fist</i>	<i>-head -face -right cheek with the right hand</i>	<i>-cheeks -head -cheek bone -front of his forehead</i>

		-forehead -closed fist	-closed fist
Specific movement in repertoire		-mom describes how he puts his arms behind his back; rocks back and forth on them	-“and again for whatever but he’ll put them right behind [shows arms behind back] and just rock on them back and forth”  +photo analysis reveals what appears to be the exact description of movement described on both accounts interestingly the child was never observed with arms behind his back in this manner in any other time.
Developing theme of what it means to be an expert and the notion of deferring to a medical authority	-“but I could be wrong because I may not understand it, I just worked with him for a week” -“but I could be wrong”  1 week	-“I don’t know I’m not an expert, this is what I’m observing” -“I’ve never had experience with this [SIB], I’m always guessing. I don’t know what I’m doing. I’m not saying what I do is correct.” -“...see it and live it everyday, you don’t know if you’re describing it correctly...”  15 years	-“Ya it’ll come out I’m a total quack... I don’t know what the hell I’m talking about” -“I could be mistaken on that like I said before I’ve only known him for you know this is my second year with him”  2 years
Bodily expression as a form of communication	-“...and because he can’t communicate in other ways, he used body language...”	-“I don’t want him to hurt himself, I don’t want this to be his main way to communicate” -“I don’t know if it’s [SIB] more of a communication tool for him or sensory, obviously a combination of many things...” -“I’m not sure that he always likes it [SIB]...but I think he uses it as a communication tool	“He is very bright. But yup communication is...I’ve said it before with communication comes less frustration, I believe that. I think that’s true for everybody whether be it a child or an adult”

		<i>partly...</i> <i>- "...obviously he's trying to tell us something"</i>  <i>+Dad describes to me how child's behavior is communicative, and he's not doing it to be aggressive, he's trying to tell us something</i>	
<i>Words to describe the repetitive behavior</i>	<i>-self-injury</i>	<i>-self-abusive behaviours</i>	<i>-self-abuse</i>
<i>Powerful comparison</i>	<i>-savage beast</i> <i>-monster</i>	<i>-high risk-criminal</i> <i>-Dad; Hannibal</i>	<i>-smoker</i> <i>-drinker</i>
<i>The emphasis on the happening of noise and hearing when describing his self-injurious movement</i>	<i>- "Hitting himself, it's the loud, most noticeable thing, it's the biggest part of his movement that people notice"</i> <i>- "He hits his hand, when I hear that..."</i>		<i>- "...you can hear it..."</i> <i>"You can hear the...the hand bouncing off the bone like you can just...you know the echo almost"</i> <i>- "It's hard to explain the sound but..."</i>  <i>+during my in home observations I write in my research journal "...as I type I can hear the smash against the bone"</i>
<i>Frequency of SIB</i>	<i>- "...60-65%, over half of the day for sure but not most of the day"</i>  <i>At camp</i>	<i>-several times a day</i>  <i>At home</i>	<i>-daily</i>  <i>At school</i>

### Cross Case Comparison and Integration

Evidence Supporting Research Question 1: Can I, as the Principal Student Investigator, identify postural or gestural cues associated with SIB in the child informant's physical movement?

Table 6

*Summary of Evidence Supporting Research Question #1*

Evidence Supporting
<p><b>Field Observations:</b></p> <ul style="list-style-type: none"> <li>• Arm waving, head cocking in saggital plane, waving of arms in distinct sustained fashion, repeated slapping of hands together, mouth pursed &amp; tightened, hitting hands to side of body, direct sustained slapping of hands together, floppy hand slap at side, fixed frozen position, punching right closed fist into open palm, palm up to front of face, sustained arm waving, head cocking, hand slapping with open palm to the floor, slapping of thighs, head cocking, hand slapping, hand waving in a sustained rotating motion, stomach slapping, left hand slap to left leg, no gaze to students, still &amp; fixed, gazing directly at students, closed fist slam into open palm, hand clapping, fast head cocking.</li> </ul> <p><b>Interviews:</b></p> <ul style="list-style-type: none"> <li>• “He hits his hand, when I hear that, I think he’ll be hitting his head next. It’s like a warning sign, or hitting one hand into another, stimming...He also makes this clicking noise with his mouth, are sounds considered behaviour? He slaps his leg a lot, sometimes by himself he grunts, I know then he’s uneasy, and when he starts to get angry, the way he moves his head and clamps down on his jaw, his eyes widen, widen and focus and when he normally he never makes eye contact” (Student Volunteer)</li> <li>• “When he, he’s very quiet, when grunting, slapping his leg, punching his own hand, sometimes he’ll tap his face before he hits himself hard, because I don’t think he wants to hurt himself” (Student Volunteer).</li> </ul>

Therefore, not only was I as a keen observer with a researcher lens able to identify body movement patterns in the child-informant, additionally the student volunteer expressed movement patterns that could also potentially be cues to the onset of self-injurious episodes. The re-occurring movement patterns within my field observations were: head cocking, sustained arm movements, slapping of the thighs, and open palms. The patterns overlapping with the student volunteer’s descriptions are: hitting his hands, hitting one hand into another, slapping his leg, and moving his head in a distinct fashion. The first finding to address is the lack of sustained movement scattered throughout the child’s repertoire, for instance, any fluid arm motions, or

Thai Chi related activities. Sustained movement appeared prior to or post self-injurious episodes and rarely was this movement engaged in otherwise. The clear distinction between the presence of sustained movement during self-injurious episodes and the absence of sustained movement during non-self-injurious episodes is an interesting finding supporting my research question. Not only have I been able to identify cues in the child's movement, but also provided meaning to the absence of these cues in his movement repertoire. The second finding is that all of the movement cues (excluding movements during self-injury) are executed with light to medium effort. Also, the hands are open and floppy not rigid and closed as they are during an episode of self-injury. Another point to note is that all of the observed and described movement patterns are directed to other areas of the body besides the most common area of self-injury: the orbital bone. The child engages in movement with the legs, open palms, the stomach, and the arms but never directly to the face. However, the only site of self-injury is to the facial region. Although the findings do not reveal either the mom, or the service worker identifying similar movement cue patterns, there may be an explanation. Myself and the student volunteer have been trained and educated in physical movement hence our observations are influenced by this theoretical and applied background. Simply because the mom and the service worker do not document the movements does not mean they are not there.

Evidence Supporting Research Question 2: Do these postural or gestural cues act as indicators of potential precursors for self-injurious behaviour in this child informant?

Table 7

*Summary of Evidence Supporting Research Question #2*

Evidence Supporting
<p><b>Interviews:</b></p> <ul style="list-style-type: none"> <li>• "He hits his hand, when I hear that, I think he'll be hitting his head next. It's like a warning sign..." (Student Volunteer)</li> <li>• "...you have to try and alter his behaviour before it escalates to something extreme. <i>What would classify as 'extreme'?</i>...like hitting his head off of something, first it starts with hitting himself, you can redirect that, a few hits to the face is nothing to him, ya because he usually hits himself 3-4 times before you re-direct it, if he was to reach the point when he hits himself off of something else, like at Marineland he threatened to hit his head off the cement pole, that is what I would classify as extreme. <i>What would you classify as mild?</i> Ummm like, when he hits his leg before he starts hitting himself, and sometimes he will just hit himself once and look at you, he's not really that frustrated yet, because I'm used to seeing him hit himself more than once. I know that he is not extremely frustrated yet, that's why it is mild. It's his segway into getting angry but not about to explode. If there is an 'extreme', <i>could you explain if there</i></li> </ul>



*is a 'moderate'?...the moderate to me is what I'm used to seeing him do. It's like when he hits himself 3-4 times. Are there any other let's call them categories? ...those classify him hitting himself, but there's another category before he starts hitting himself when he is shaking his head back and forth, and clicking his teeth and grunting, I don't know the name of the category but those are the signs before it turns to mild moderate or extreme" (Student Volunteer)*

**Figures: *Tree of Communication***

- There appears to be distinct categories of difference in the child's bodily expressions. Each of the participants during the interview resorted to using a categorical system of classification with a range of movements.

These cues most certainly suggest the potential to be pre-cursors to episodes of self-injury. There is evidence that these cues are indicators when the student volunteer states: ...“it's like a warning sign”. She declares that bodily movements she observes are assisting her to predict the likelihood of the child once again engaging in an act of self-injury. An interesting point to note is that novel pre-cursors of clicking his teeth and grunting have been presented in the interview of the student volunteer. These cues may have been overlooked in the field because of limitations of proximity to the child's body. This emphasizes the strength of the study being triangulated. Based solely on field observations, I may have overlooked re-occurring movement patterns that can only be observed a meter in distance from the child. The distance I conducted field observations from limited my potential to hear the body. However, the design of the study addressed this issue. My observations were compared against the student volunteer's observations at camp. Based on the evidence presented it appears that the pre-cursors are the intensity and the frequency of the hitting increasing. When these pre-cursors are engaged as a form of communication a child with no verbal repertoire begins to clearly communicate through his body. For instance, in the aforementioned scenario the student volunteer states the child was threatening to do something. Since he does not use vocal mannerisms, he is clearly communicating threat through his body language. And if his bodily movements are communicating an idea they appear to be strategic and deliberate.

Evidence Supporting Question 3: Could the study of these physical cues provide development of a more comprehensive approach to redirecting self-injurious behaviour in this child informant?

Table 8

*Summary of Evidence Supporting Research Question #3*

### Evidence Supporting

#### Interviews:

- "...so when you see his repetitive behaviour, you know it's time to give him a break, but it can't be right way or if every time he did it we gave him a break, he would think it would get him out of what he was doing..." (Student Volunteer)
- "...it's hard to explain. I guess just because I know him. You know I just live with him, I know what his triggers are, I know when he's upset, I just I dunno probably...it's like working on a machine or a car you get to know it, like a mother's intuition, I can't explain." (Mother of child)
- "...you have to try and alter his behaviour before it escalates to something extreme. *What would classify as 'extreme'?*...like hitting his head off of something, first it starts with hitting himself, you can redirect that, a few hits to the face is nothing to him, ya because he usually hits himself 3-4 times before you re-direct it, if he was to reach the point when he hits himself off of something else, like at Marineland he threatened to hit his head off the cement pole, that is what I would classify as extreme. *What would you classify as mild?* Ummm like, when he hits his leg before he starts hitting himself, and sometimes he will just hit himself once and look at you, he's not really that frustrated yet, because I'm used to seeing him hit himself moer than once. I know that he is not extremely frustrated yet, that's why it is mild. It's his segway into getting angry but not about to explode. If there is an 'extreme', *could you explain if there is a 'moderate'?*...the moderate to me is what I'm used to seeing him do. It's like when he hits himself 3-4 times. *Are there any other let's call them categories?* ...those classify him hitting himself, but there's another category before he starts hitting himself when he is shaking his head back and forth, and clicking his teeth and grunting, I don't know the name of the category but those are the signs before it turns to mild moderate or extreme" (Student Volunteer)

#### Interpretations:

- Informed by the evidence from content analysis of question 2, absolutely these categories are evidence of the need for information to be strategically presented in a comprehensive manner. The participants naturally are developing their own categories when giving explanations of the movement, this is further evidence of the usefulness of developing a comprehensive tool that can assist in interpreting these categories of movement.

It would be incredibly challenging to train school personnel and new student volunteers using either “mother’s intuition”, or solely on an unspoken talent to understand what the child is communicating. This again emphasize why it would be incredibly useful to gauge the trained movement-theoretical eye by developing a comprehensive back to basics coding system of Laban’s movement principles. Instead of requiring four years studying movement theory to understand what one is seeing as the body communicates, one can be trained on how to use the gestural coding system and learn how to understand what the body is communicating. The dissemination of knowledge acquired in a university degree, can then be accessed by those that need it the most; the individuals working directly with the child.

#### Evidence Supporting Question 4:

- How can the child informant’s physical movement be engaged as a form of communication?

Table 9

#### Summary of Evidence Supporting Research Question #4

Evidence Supporting
<p><b>Field Observations:</b></p> <ul style="list-style-type: none"> <li>• Post self-injurious episode, the child touches the area of injury with fine, light effort. The movement quality is distinctly different then the movement during or prior to the self-injury. It potentially indicates that he does not want to hurt himself and these claims are further supported by the data collected during the interviews.</li> </ul> <p><b>Interviews:</b></p> <ul style="list-style-type: none"> <li>• “...because I don’t think he wants to hurt himself” (Student Volunteer). A direct quotation found during phase two of analysis to be a powerful phrase.</li> </ul> <p><b>Analysis:</b></p> <ul style="list-style-type: none"> <li>• Derived from content level analysis of observations and directly related to the history of the child. He has been engaging in this behaviour all his life, so is this is in fact a form of communication.</li> <li>• There is a limited amount of hard evidence, however here is a descriptive history of his bodily expression, here is the raw data acting as supporting evidence for my final research question:</li> </ul> <p>1-infant; “I don’t know...but it’s funny from birth I knew something was up. Not self-abusive, just, having other child first, you do compare there was just different things that he did that were odd...”</p>

2-age four; rocking with his hands behind his back, his head always up against a hard surface, he used to do this in his crib, head-banging, specific incident where smashed his head off the wall in the kitchen

3-grade five or six (10 or 11 years old); face-punching began; "Umm, I think it kinda started by accident...", "...again now I can't really pinpoint when I noticed it, and I don't know what or can't recall what lead up to it, but it's a behavior he started, maybe he picked it up from school..."

4-age fifteen; "would be either him head-banging, banging his head against wall or surfaces, floor or wall, could be tv unit, the door frame, a chair, the counter, the fridge...oh ya windows, well the bus ones... French doors, oh the face punching oh and biting..." "...and again from that day on, it just kind of expanded...doors, doorframes, counters"

If I am able to identify pre-episodic cues this suggests ways the child's body can be engaged as a form of communication. It is about trusting his body and what it is communicating and making connections with his body to his use of sign language. When his body becomes rigid, when he begins having a heightened sense of eye scanning and sustained arm movements he is physically vocalizing to his environment. A visual gestural communication repertoire appears to be important to the child-informant. He does ultimately rely on his physical repertoire as it is his only form of functional communication. If a tool can be developed so that it engages and utilizes the non-verbal body as site of communication this can be potentially be useful across numerous domains and numerous children, for instance, children who are selectively mute. This tool would be a paper and pencil, user-friendly template that guides keen observation in the individuals in the child's life. Further studying the non-speaking body and ways of expressing that take precedent over and above speech and focusing greater attention on these different forms might be helpful. The ultimate goal is to understand self-injury and the evidence suggests that the child-informant in fact does have forms of self-injury that deliberately communicate an idea that cannot be verbally vocalized.

### **Data Set B Patterns**

This data set includes the coding system, movement profiles, and raw data charts compiled from data collected during field observations. The objective of this section of data was to focus on the movement qualities of the child. The process of this data set began as raw data, reduced to charts, reduced further into the generic coding system and augmented by the daily movement profiles that were also taken as raw data.

Once the gestures were written and coded I analyzed through visual inspection patterns in the self-injurious episodes. The most prevalent patterns I observed during my analysis were the following (see table 10).

Table 10

*Gestural Coding System Data Patterns*

<i>Data Set</i>	<i>Patterns Within</i>
Coding System	<ul style="list-style-type: none"> <li>• Over the course of the week, the child engaged in symmetrical self-injurious behaviour using the left hand to direct force onto the left side of the face, and the right hand to direct force to the right side of the face.</li> <li>• He favors the left side 8 to 7.</li> <li>• The most frequent location/ site of the self-injury is along the orbital bone (beneath the eyes, high on the cheek just below the temple).</li> <li>• He favors direct, hard effort.</li> <li>• He favors a closed fist.</li> <li>• All episodes with exception of two were above the neck; the other two were on the leg.</li> <li>• External objects were used infrequently to cause the self-injury but when used were always heavy in weight.</li> </ul>

In addition to the field notes that were taken, a daily movement profile was used to augment the details written in the field notes. The patterns presented are the areas the child has dominances (strengths in his movement quality and frequency) and gaps (weaknesses in his movement quality and frequency). The gaps are based on both his lack of movement experiences and his genetics (muscular, coordination, flexibility). Once again, *italicized* movements are areas for further discussion and were patterns found both within and across the data set. These are presented below (see table 11).

Table 11

*Movement Profile Data Patterns*

<i>Data Set</i>	<i>Dominances Patterns</i>	<i>Gaps Patterns</i>
Movement Profile:	<ul style="list-style-type: none"> <li>• Bending</li> </ul>	<ul style="list-style-type: none"> <li>• Stretching</li> </ul>

<i>Body</i>	<ul style="list-style-type: none"> <li>• <i>Gestures</i></li> <li>• Landings onto the back and bottom</li> <li>• Transferring from sit to stand</li> <li>• Walking</li> <li>• Body parts leading/focusing</li> <li>• Body parts meeting and parting</li> </ul>	<ul style="list-style-type: none"> <li>• Twisting</li> <li>• Curling</li> <li>• Weight bearing on his feet</li> <li>• Gliding or sliding</li> <li>• Maintaining balance</li> <li>• Regaining balance</li> <li>• Running, hopping, skipping, creeping</li> <li>• <i>Decelerating</i></li> </ul>
Movement Profile: <i>Space</i>	<ul style="list-style-type: none"> <li>• <i>Forward</i></li> <li>• <i>Direct</i></li> <li>• <i>Close reach</i></li> </ul>	<ul style="list-style-type: none"> <li>• Medium levels</li> <li>• Low levels</li> <li>• <i>Backwards movement</i></li> <li>• Movement from right to left</li> <li>• <i>Far reach</i></li> </ul>
Movement Profile: <i>Effort</i>	<ul style="list-style-type: none"> <li>• <i>Firm weight</i></li> <li>• Fine weight</li> <li>• <i>Sudden time</i></li> <li>• Bound flow</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Sustained time</i></li> <li>• <i>Free flow</i></li> </ul>
Movement Profile: <i>Relationships</i>	<ul style="list-style-type: none"> <li>• <i>Alone</i></li> <li>• Sending</li> <li>• Receiving and stopping</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Groups</i></li> <li>• Implements</li> </ul>

The analysis of the data indicates that the child has many more gaps in his movement repertoire than he does dominances. What does this mean? Possibly it could further indicate the notion that the child has a limited repertoire and the repertoire he does rely on is not fully understood, or it is not fully being engaged as a form of communication and should be. It emphasizes the need to fully engage and understand the repertoire he is currently relying on. This way movement goals and re-directive strategies could be created specifically based on expanding the child's movement repertoire.

Specific dominances that are important to note are first of all: his use of gestures. Every day, gestures were always the most frequent movement and were of movement quality. In addition, his use of forward, direct and close movement is consistent with his self-injurious movement. I observed him utilize these dominances in movement in both instances of self-injury and instances of non self-injury. However, it is interesting that sustained movement was observed as a gap. In data set B part b, it was found that a possible pre-cursor to an act of self-injury was sustained arm waving. This was confirmed by the analysis of data set A part a and b. Despite it often being a movement expressed prior to episodes of self-injury it remains a gap

because it is not observed in any other instance other than during self-injury. The repetitive sustained movement pattern that is distinct as a pre-cursor is never utilized in general movement activities even ones aimed at providing opportunity for sustained movement such as Tha Chi. Also, it is important to emphasize the relationships between the child and his peers, and other apparatuses. Most of the activities the child engages in are alone. This is evidence that this movement frequency dominates the child's movement repertoire and that he rarely engages in co-operative play with his peers.

## **Comparing and Confirming Research Typologies**

### **Site of self-injury on the body**

A review of the literature on the most common sites of the body on which self-injury is inflicted in a population of individuals with developmental disabilities has confirmed that slapping and banging the front of the head, and biting the back of the hands is most frequent (Symons & Thompson, 1997). An interesting finding to note from Symons and Thompson's (1997) research is that although individuals have full access and exposure to other areas of the body, only a small percentage of their self-injurious acts are directed and used for sites of self-injury. This is consistent with the current research findings where the most common site of injury is to the front of the head and with a preference for hard, direct force. A possible theory explaining this phenomenon is that the head is accessible, and within close reach. This is evidence supporting the notion that in at least some episodes the self-injurious acts are of a deliberate, planned nature. The child chooses specifically and strategically where to deliver the force having possibly been reinforced automatically, by escape or by social attention. Might these episodes look differently if the function of the behaviour is different? Certainly. Phase three of analysis has indicated that self-injury specific to the child-informant in fact has at least two distinct topographies. This has been confirmed by two of the three data sets, specifically the interviews and the field observations.

### **Generic body image as form of movement tracking**

The use of a coding system to track and consequently analyze on a daily basis a child's self-injury in the home, school and recreation settings has previously been utilized and supported. Symons and Thompson's (1997) came to the conclusion after using a similar self-injury grid that descriptive data on self-injury site is valuable both theoretically and clinically. If this value could be extended to successful applications educationally and recreationally it could develop numerous opportunities for a number of children who have traditionally been excluded from meaningful participation.

### **Categorizing self-injury versus continuum of self-injury**

Based on the direction of the emerging patterns I have chosen to review literature on different forms of self-injury-exploring this notion of continuums and how although definitive

differences between self-injury are apparent in both the public eye and in literature, the line of definition is blurred to what defines acceptable self-injurious acts. Ones that do not horrify the general public? Ones that the public has heard? For instance, religious self-mutilation in the form of flagellation, stigmata, cutters (possibly a glamorized form of self-injury?), excessively biting nails, picking one's scabs to the point of bleeding, body piercings, tattoos, cultural self-injurious acts like tattooing on the face, large heavy rings around the neck. The point being, although not exhaustive the list is extensive. Symons and colleagues (2005) reduce these differences down to the simplest form when they explore the idea of normal versus abnormal movements (Symons et al., 2005). It seems that the classification of 'normal' is acceptable ranges of self-injury to one's body such as nail biting, picking scabs, and biting the inside of one's cheeks. But once this behaviour extends beyond this acceptable range it becomes horrifying and abnormal. It may in fact not even be the categories of acceptable versus unacceptable or normal versus abnormal but rather, which forms have had the most public exposure.

Interestingly, the notion of breaking through categories and developing a continuum emerges through Muehlenkamp's (2005) research when she reviews the idea of deliberate self-injury belonging to an entirely separate category in the Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> Edition. She also explores the similarities and differences among and between individuals who self-injure and those that are suicidal presenting that the phenomenological features of the two are inherently different (Muehlenkamp, 2005). Interestingly the features of eating disorders and self-injury are inherently the same (Muehlenkamp). The implications of this on the child-informant would be a dual diagnosis of: Autism, deliberate self-injury in addition to deafness. Could the development of this new category affect how the child-informant is treated? Likely no. Does it assist in understanding the nature of self-injury? Potentially it could be addressed differently if it were deemed a disorder in and of itself not a by-product of another developmental disability.

Although this information is insightful and provides evidence of a continuum of self-injury that is not yet firmly established, another area of discussion emerges. In a recent review of self-mutilation acts, engagement in the acts by individuals with a disability is excluded from the category: deliberate self-harm (Mangail & Yurkovich, 2008). The argument within this review is that self-injurious behaviours of individuals with a serious psychopathology are only biologically motivated (Mangail & Yurkovich, 2008). For instance, a physical motivation to hit oneself simply for the sensory by-product it produces. Could this simple explanation be sufficient? I beg to differ. My findings support this notion.

### **Distal versus medial self-injurious acts**

I have continued to review the literature on cutting as an act of self-injury. An interesting point to note is this possibility that cutters injure on the distal portions of the body where as children with Autism commonly injure on the medial vulnerable areas which are home to all the senses. Although no formal literature supports this, another point of discussion is embedded



within this particular pattern. The self-injurious acts may not correspond to distal and medial parts of the body, but in fact correspond to the effort or intensity used on the body. Slight and sharp effort is often used in individuals who identify as cutters (Lesniak, 2008). The tools that assist in this effort are needles, razors, broken glass, lighters, and pencils (Lesniak, 2008). In contrast, my findings reveal that hard, fast, intense effort dominates my child-informant's self-injurious repertoire. Any time an external object was used it was dense and large for instance, a heavy medicine ball, a doorframe, a glass window. Some of the elements are the same glass, and metal, but the form these natural objects are in varies dramatically.

### **Epistemic invalidation**

It became apparent through analysis phase one that whether it is two years, a week or a lifetime, not one participant fully adopted ownership and authority over their level of expertise and experience with the child's self-injurious acts, not even the mother. This is consistent with Wendell's (1996) notion that the authoritative power of an 'expert' is so pronounced it overpowers a lifetime of personal investment and experience. When not one person in my research project was designated the 'expert', this abstract role became the authoritative power by default. Historically, individuals have become accustomed to cowering in the presence of experts (Wendell, 1996). Unfortunately, it is this exact power that weakens the depth and understanding required to move forward with research on self-injurious behaviour.

### **SIB as a form of communication**

The essence of this research project is to understand the child-informant's self-injurious episodes as a form of communication that can be gauged and designed into a communicative tool useful across numerous domains in his life: home, school and recreational settings. This theoretical notion has been concretely presented in the form of a visual The Tree of Communication (see appendix Figure 1). This visual is a preliminary design of a communicative tool that can be standardized and used across domains in the child's life. The literature supports this notion that SIB functions as a communicative outlet. First of all, Favazza and Conterio (1989) find that rates of SIB occur because of an inability to express feelings. The physical communication overrides the vocal communication. Either way, the behaviour's aim is to communicate. Favazza (1998) also suggests that individuals engage in SIB because of an impulsivity; a raw cognitive state that expresses itself outwards in the form of various self-injurious acts. In addition, Zlotnick and colleagues (1996) also found a relationship between engagement in SIB and Alexithymia: a difficulty identifying and describing emotion. All three of these descriptive characteristics support the notion that when an individual has difficulty expressing himself in traditional vocal mannerisms, he begins to find different means of communication: physical ones in the form of self-injurious behaviour.

The dominant theme in the literature was that the participants that were interviewed that could vocalize their lived experience of self-injury indicated that at the time, it was a means for

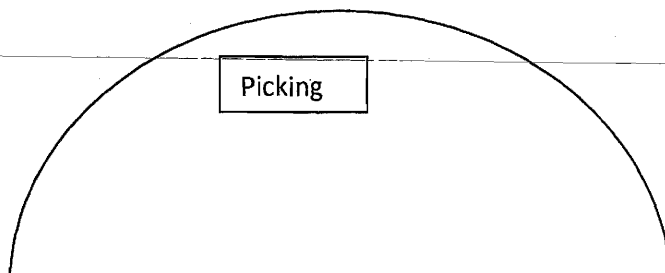
them to communicate an idea or emotion that they could not express verbally. This theme suggests these particular physical actions are louder than any vocalization could ever be. I also found two powerful descriptive statements describing self-injury as communicative. The first powerful statement is from Machoian's (2001) qualitative work found during interviewing one of the three adolescent girls in her study. The quotation presented reads: "It's, it's an actualization of pain, you know...The most basic is that even if you tell people that something is wrong, a lot of times, they won't, they won't know how wrong. But all they'll do is see a cut along a vein, and they get the message right away" (p.25). This is an incredibly loud statement, with an underbelly of an array of issues, the focal point for my research being the intensity of the physical statement. The focus on what the physical action means. As for my child-informant that is my ultimate goal, to gain insight into what he means when he expresses himself physically.

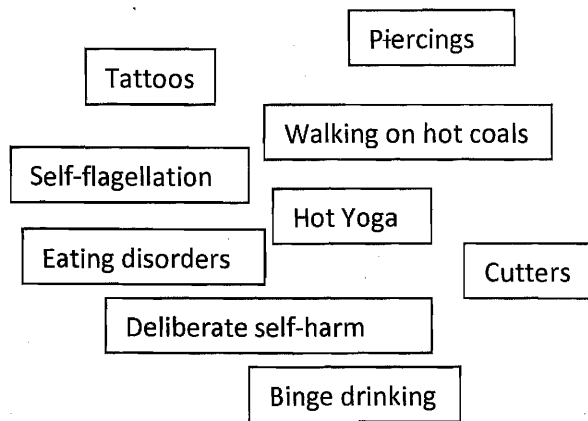
The second powerful statement was made by the researcher themselves when Potter (2003) expresses "...that the body is being used as text and serves to communicate something that is difficult to articulate in conventional modes" (Potter, 2003 as cited in Mangnail & Yurkovich, 2008). So the point is that it appears various individuals reduce their feelings to the most basic form and communicate them physically. This, in my qualitative eyes is no different than a child who cannot communicate vocally utilizing SIB as a form to communicate possibly even the most basic of emotions, feelings and concerns such as *I am anxious*, or *I don't want to do this anymore*.

It is apparent from a review of the literature that SIB is often used as a means to communicate an idea, emotion or feeling that cannot otherwise be expressed vocally. That is even in individuals who do speak and communicate vocally, SIB remains a meaningful expression in their movement repertoire. This provides insight into the notion of attempts to eliminate SIB versus attempts at understanding what SIB is ultimately communicating.

### **Prevention versus acceptance: Exclusion of individuals with disabilities from self-injurious continuum**

During the review of the literature, I have found an extensive amount of information on deliberate self-injurious behaviour as it pertains to individuals without developmental disabilities. However, the continuum of inclusivity for individuals who deliberately self-injure and have a disability is sparse. Self-injurious acts engaged in by individuals with disabilities are aimed at prevention and reduction of the acts because according to the literature they are deemed repetitive and biologically driven. In contrast, self-injurious acts engaged in by individuals without disabilities have morphed into acceptable acts often bound by culture. On the following page there is an image to depict what I have found:





- Self-injury in individuals with a developmental disability.

## CHAPTER FIVE: Discussion

The purpose of this case study was to answer a series of four questions that reduce down to one main concept of communication. As a researcher I asked if I could observe a non-verbal gestural repertoire in a child that could then potentially be gauged as a form of communication. I was able to translate the child's non-verbal repertoire with the use of diagrams and a coding system and develop it into a form of communication. The communicative tools I chose to represent this proposed form of communication are user-friendly, and rely on this use of basic

visuals. The objective was to seek ways that this gestural repertoire could be translated so that the individuals in the life of the child informant could better understand his wants and needs. Ideally, understanding his wants and needs could help reduce the frequency and intensity of his self-injurious behaviour because its communicative properties could be better understood. Once it is understood, other functional forms and choices on how to communicate that are the least harmful can then be implemented. First and foremost, I found that there was a distinct pattern of self-injurious behaviour that could potentially be gauged as a form of communication. This finding was demonstrated by the development of the tree of communication (see appendix A, figure 1.0). The implications of this original finding are two-fold. One, the findings suggest that self-injurious behaviour in this young male are more often than not deliberate and engaged in frequently with a purpose to communicate an idea. Two, these results provide evidence that there is in fact a continuum of communication, and self-injury that must be further explored in detail. This discussion will thoroughly address the themes that the findings have been distilled into as each of the four research questions are simultaneously interrogated. The discussion will be presented in chronological order as the findings emerged.

### **Field Observations**

The course of my research project began with detailed observations in the field. I proposed to keenly observe the child-informant naturally in settings where he was engaging in movement and physical activity was being facilitated. I additionally proposed to video-record these events. One of the most prominent findings during my observations was, outside of this specialized movement camp, the child had little to no opportunity to expand his movement repertoire, and to engage in modified or pre-requisite movement skills for physical sport. He did frequently engage in walking while at school and the mother of the child continued to seek movement opportunities in the community for the child such as swimming and bowling, but the presence of these programs were sparse. These initial findings are consistent with the literature on opportunities for physical activity for the population of children and youth with disabilities such as Autism Spectrum Disorders (ASD). As I too found in my initial review of adapted physical activity, Pan and Frey (2006) declared, in their research exploring patterns of activity in youth with Autism Spectrum Disorders, that: "it is clear that people with ASD have been excluded from the physical activity literature" (p.597). Initially, this posed an immediate challenge for my literature review that would lay the foundation for the growth of my research project. How was I to review information that was so sparse it was deemed non-existent? There is such a limited scope of published work exploring physical activity in the population of individuals with ASD and it only exacerbates the risk of these youth developing sedentary lifestyles (Pan & Frey, 2006). This consequently leads to these children become overly obese, even further restricting their opportunities in physical activity (Pan & Frey, 2006; Murphy & Carbone, 2008). Children with ASD already have challenges with the core principles of movement such as relationships with objects and others (social interaction) (Pan & Frey, 2006), this would then seemingly suggest the immediate need for research incorporating physical

activity in this population. Although I regrettably inform that the research is lacking, I alternatively have produced this case study to attempt to direct attention to this area of study. In addition, to suggest ways in which teachers, volunteers and parents can begin to increase physical activity opportunities for these children who have historically been excluded from it. In this particular case study, the suggested strategy being translating communicative movement and utilizing this to facilitate more opportunities in physical activity. The field of physical education aims to teach individuals about their bodies, how they move and help the student learn meaningful and safe ways to express emotions such as anger, sadness and frustration. Without knowledge and an understanding of the student the teacher works with, participation in physical activity will potentially be unsuccessful. Yet again, the aforementioned highlights the importance of the present research. Most specifically the gestural coding system (see appendix figure 2)- it potentially fills a void in the current body of literature. As it aims to help understand the complexities of the student's movement, and increase the chances of him being provided opportunities for participation in physical activity.

During the outset of the field observations, I as a researcher also came to the understanding that video-recording would reduce the amount of detailed observations I was able to make on the limited scope of movement activity I had access to. My observations would lack a holistic description of all the senses; ones that potentially could have been lost in translation through video-recording. I made the executive decision to protect the observations of movement that I was able to make. This also would help contribute to the extended practicality of observing movement in children with Autism since most teachers, volunteers and service workers would not have access to video-recording equipment and they too would only be able to rely on their own observation skills. This in hindsight contributed to the successful development of the first gestural movement translator the gestural coding system (see appendix A, figure 2). This would continue to develop into one of the most valuable and practical tools for dissemination into the network of individuals in the life of the child-informant.

## Interviews

The first interview conducted was with the student volunteer mid-week during the movement camp. One of the most interesting findings from this interview was the powerful phrase of: "...because I don't think he wants to hurt himself" (Student volunteer Sept 1, 2010). This phrase was initial evidence of the theme that the self-injurious behaviour is a form of communication. The phrase suggests that the child in fact engages in severe self-injurious behaviour but that the hurt and damage caused by the action may only be a by-product of the behaviour not the motivation driving the occurrence of the behaviour. It is an important finding because of its chronological positioning at the outset of the research project. Right from the beginning data is suggesting there is a strong indication of the communicative properties of the child's self-injurious behaviour. In addition to this finding, when describing the repetitive behaviour of the child the student volunteer uses the phrase: "...his eyes widen, widen and focus when he normally never makes eye contact" (Student Volunteer Sept 1, 2010). This phrase

provides evidence that there are additional gestural cues that are distinctly different when he is engaging in self-injurious behaviour in comparison to the gestural repertoire that he expresses when he is not engaging in self-injurious behaviour. This information contributed to the development of the tree of communication (see Appendix A, Figure 1). Without access to the keen observations of this student volunteer the accuracy and value of this translating tool would be reduced.

The second interview conducted was with the mother of the child. The most useful findings from this interview were the use of metaphor to describe what living with and through a child with Autism is like. The struggle to find descriptors and to convey a real lived experience was evident through this interview. This finding suggests that the public's knowledge of Autism and understanding the experience of living with Autism is limited. It indicates the importance of conducting case study research that can unveil descriptive detail that is otherwise secluded to the small community of individuals who have experienced similar circumstances. Such metaphors were comparing the child to a machine or a car; how one becomes familiar with their own everyday experiences and objects they interact with on a daily basis and that the idiosyncrasies of this machine. A possible theory to explain this particular metaphor is the notion that North American society aims at fixing and terminating any behaviours that are not within the norm and considered abnormal. Even the mother of the child has an internal struggle with wanting to 'fix' her child, because this is what society has been repeating to her. It speaks volumes to the value that North Americans give to those living with disability. In addition, describing the experience of being a parent of a child with Autism to the notion of a war veteran. One can truly only understand and freely discuss the darkest hours of the *battle* with those too who have experienced it themselves. These findings are important because they suggest the difficulty in abstractly communicating the complexity of Autism. Interestingly enough, the very children who live with Autism also have difficulty communicating their own ideas. Yet again, this suggests the need for a translating system that works bi-directional so that all persons can communicate more effectively with each other.

The final interview was conducted with the service worker of the child. In essence, the interviews have triangulated the community, the home and the school. Information in the form of interviews has been extracted from all three of these settings. The most prominent finding in this final interview was the intensity of the child's self-injury. The findings confirm the severity of the behaviour, and the immediate need to develop tools and deliver strategies to the network of individuals in the child's life. This is so that he can be provided alternative forms of communication that do not harm his body.

In summary, the main findings from the three interviews were that the self-injurious behaviour is severe, it has communicative properties and that its essence is difficult to articulate to individuals who do not specialize in movement or disability studies. All three of these findings reiterate the need for a tool that can potentially gauge the behaviour as a form of communication,

reduce the intensity and frequency by re-directing the behaviour and provide meaning to the complexities of the movement to an untrained audience.

The findings revealed six categories that were consistent across the interview data sets. In the analysis, these categories were thoroughly explored and augmented by literature that further explained the phenomenon in detail. It is necessary to investigate further the deeper meaning behind these distinct categories.

### **How does SIB affect the child's life?**

The first category was a response to the social question *how does the SIB affect the child's life?* Both the student volunteer and the service worker made a clear reference to the notion of 'cutters'; a self-abusive act researched in the non-disabled population describing the act of cutting with sharp tools usually to the insides of the arms, and legs. The literature suggested that the act was typically private, and the tissue damage was on areas of the body that could be hidden (Lesniak, 2008). In contrast, the child's SIB is very public, and primarily targeted to the region of the head. Any tissue damaged caused by the child's SIB would clearly be visible, and interestingly in my observations were deliberately touched with distinctly light effort post self-injurious act. The child would intentionally rub or hold onto the area that had been repeatedly smashed to once again communicate: *what I am doing hurts, look at me this hurts*. It is as though during the moment the most accessible means for the child to communicate is to engage in the behaviour he has always known. After the act, the tissue damage by-product is yet another form of communication. The more subtle gestural cues the child expressed prior to the episode are not easily identified, but swelling, redness and bruising are much more universal for *I need help*. It is as though the child has a very high tolerance to pain and that the injury site is not held onto because it primarily hurts, but because it loudly communicates to its audience. Therefore, this categorical finding indicates that a tool needs to be designed so that those cues are identified and the child can effectively communicate his needs with a less harmful means than an episode of self-injury.

**Place site of the SIB.** The second category was the targeted self-injury site. There was a very strong correlation between all three adult participants: the student volunteer, the mother of the child and the service worker of the child. All three participants indicated the site of injury was on the head, and more specifically the forehead, cheek, and with a closed fist. This finding is of particular interest because it indicates that there is minimal variation to the topography of the behaviour. The effort of the self-injurious movement is consistently hard, direct and sudden. As the service worker describes it: "...he'll [the child informant] just bruise those cheeks because he hits them so hard" (p.13) and as the mother describes it: "I guess from what I see most people would look at it [act of SIB] and be horrified" (p.9). The act is so intense it frightens and horrifies adults. The same site of injury is repeatedly hit until bruising occurs. An interesting point to note is all the sites described are on very solid, bony surfaces on the face. The forehead is essentially the frontal bone of the skull and the cheek is primarily the orbital bone

just beneath the eye. Considering the co-morbidity of the child's Autism and Deafness this may potentially indicate a complexity influenced by the Deafness. Smashing solid bones in the area of the head will likely result in strong vibrations in the ears. In essence the child's injury sites may be his loudest form of communication even for him. The fact that the injury sites remain consistent suggests its communicative properties. Since the movement profiles of the child during camp indicate he does have a larger repertoire of movement besides hard, direct and sudden, the form and effort is likely purposefully chosen for the most intense by-product.

**Deferring to an expert.** Susan Wendell (1996) describes the concept of an expert taking precedent over the lived experience of individuals and this concept's presence is clearly evident in my findings. Phrases such as *I could be wrong, I don't know* and *I could be mistaken* litter the responses of all three of my adult participants. The phrase often utilized at the outset of providing a response or after a detailed response had been given. It would be interesting to compare results if I had entered the interview and established an imbalanced power relationship with the participants-would I have then been considered the authoritative power? Diagnosis of disability is conducted by individuals trained in the medical model and yet it is the social-political-cultural features that contextualize the experience of these individuals' lives. This finding suggests the importance and need to disseminate information and make it accessible to the individuals who need it; the families and individuals living with Autism. Research becomes useful when it can be translated and accessed by the public. A case study such as my own aims to do just that-make valuable information accessible.

**Form of communication.** One of the most important findings was the re-occurring pattern that each participant described the self-injurious acts as communicative. The student volunteer described how the student relies on communicating and reading body language. Both the mother and additionally the father of the child describe how their son is trying to tell them something when he engages in this behaviour. While the service worker emphasizes that frustration is dramatically reduced with communication; the reciprocal act of sharing an idea from one person to another. This finding justifies the search and development for a tool that can monitor behaviour and translate it so that it reads as communicative in nature.

**Powerful comparison.** An alarming finding was the analogy's used to describe the perception others have of the child: a drinker, monster, high-risk criminal, and Hannibal (a cannibal eating killer) among many others. The fact is that many people perceive the child to be dangerous and malicious because of the intensity of his self-injurious actions. This finding emphasizes the immediate need to eradicate misconceptions about children who self-injure and remind the public that the nature of self-injurious behaviour is that it is an act directed towards oneself not others. Can you imagine how you would feel walking into a room all eyes on you assuming that at any moment you may lash out in aggression onto any unassuming individual?

**The terminology.** Another interesting finding during the exploration of my research was the words to describe the phenomenon. The lack of consistency on what to call the



phenomenon could potentially be another reason why there is a lack of public knowledge about it. Even within my participant population of three, variations of the phenomenon were used: self-injury, self-abusive behaviours and self-abuse. In addition, during the scope of my research another handful of words were used: repetitive behaviour, and self-destructive behaviour. Each word has specific connotations and implicit meanings attached to them. Which to use? As a researcher and interviewer I chose to find deeper meaning of the phenomenon by asking the participant to label the behaviour as they typically do. This allowed me to explore this finding in further detail than if I were to have just called the behaviour self-injurious from the beginning. I was able to gain more insight into the lived experience by using and trusting the words of my participants.

**The sound.** An additional finding that was of particular interest to me was the concept of sound used to describe the child's physical self-injurious behaviour. Typically, a physical movement would be described with action words predominantly relying on the descriptors of sight. In this case study, the participants and even myself in my research journal, continuously relied on the sense of sound to describe the child's self-injurious behaviour. Of most disturbing influence was the sound of cracking, and bouncing of a closed fist against bone. Again, an ironic finding since the child himself due to his Deafness does not hear the action as most others do in his surroundings. This finding simply re-iterates the intensity and force behind the self-injurious acts, he is smashing so hard that the sense of sound is the most dominant feature. This also suggests the immediate need to re-direct the behaviour, as not to cause further permanent damage to the child's bone structure, and nervous system.

### **Photo Document Analysis**

The main findings from the photo document analysis were confirmation and expansion of the gaps and dominances in movement data from the movement profiles sheets. Most specifically the findings confirmed the following dominances: gestures, forward and direct movement in space, close reach, firm weight, sudden time and alone. The implications these findings have are firstly, the child's self-injurious behaviour relies on his dominant movement repertoire. An episode of SIB is direct, firm and engages on his body (alone) just as his movement profile sheets from the sheet indicate these are dominances in his general movement. If his movement repertoire is expanded this could potentially help develop more dominances in his movement—ones that can substitute the harmful full—body force he is currently relying on. This could potentially reduce the intensity and harmfulness of his current self-injurious behaviour. In addition, the findings from the photo documents confirmed the following gaps in the child's movement: deceleration, backwards movement, sustained time, free flowing movement and movement in groups. Again, an expansion targeting these gaps in his movement could potentially create more body awareness and provide a larger mechanism to communicate from. For instance, if the child could learn to differentiate between direct hard effort and indirect light effort he could potentially manage his body more effectively and find new less harmful ways of communicate an idea to the individuals in his life.

### **The Gestural Coding System: The self-injurious behaviour**

The gestural coding system revealed that the child's self-injury is typically engaged in a uniform, consistent manner. He targets the region of his head, specifically the side of the face and the forehead. An episode typically consists of 3-4 intense smashes to the face. He favors direct, hard effort confirming the findings from both the photo documents and movement profiles. An interesting finding is that on occasion when he utilized an external object to cause self-injury the objects were always heavy in weight for example a medicine ball, and wooden balance bench. This finding emphasizes the deliberate and conscientious nature of the child's self-injury. In the movement camp setting there were numerous objects that were firm yet light for instance, foam objects, crash mat, and trampoline. The child had equal, if not more access to these items and yet the child never utilized these objects in an episode of self-injury. Any instances of complete absence of a movement are of particular interest because they reveal a strong reliable movement pattern. Again a possible explanation for the deliberate use of hard, dense objects could be the desire to hear the vibrations and by-product of the action. If the child is hypo-sensitive and deaf, he may be motivated to engage in actions that he can feel with his body and hear hence the hard, direct effort with heavy objects.

### **Answering the Research Questions**

**Number one.** *Can I, as the Principal Student Investigator, identify postural or gestural cue associated with SIB in the child informant's physical movement?*

The findings of my research project revealed in both my field observations and interviews that I was able to identify a specific category of gestural movement that was predominantly expressed post and prior to a self-injurious episode. These specific movements that were present across the data sets I have categorized as cues and include the following: hitting his closed fist to his alternate open palm, hand slapping on his thighs with quick, hard effort, sustained arm-waving or slapping and head-cocking in the sagittal plane. The implications of these findings are they can potentially help guide individuals in the child's life in recognizing his likelihood to engage in self-injury. There is the potential to further explore these cues to determine if they are expressed strategically in different contexts. I have carefully observed his movements, identified cues and now translated these cues into the communicative idea: *I am feeling the intense need to tell you something, pay closer attention to what my body is telling you.* This idea has been developed into the tree of communication, a tool that can be further developed, modified and expanded for its practical use in the community, in the school, and even in the home. The development of this tree of communication was influenced by the mother of the child's statement that she knows and can often predict her child's behaviour simply with intuition. This tool is a mechanism by which this intuitive sense can be concretely engaged and practically utilized for the success of the child in the community.

**Number two.** *Do these postural or gestural cues act as indicators of potential precursors for self-injurious behaviour in this child informant?*

The findings of the present case study indicate that in fact after keen observation and an extensive exploration of the child's gestural and postural cues that there are distinct categories of behaviour that indicate the potential for an episode of self-injurious behaviour. Interestingly, these indicators were naturally created by the participants themselves as they described how the self-injurious behaviour looks, how they learned to predict and re-direct the behaviour in their own interactions with the child. The implications of these indicators are that they lay the necessary foundation for a comprehensive tool to be designed. I first asked if the presence of these cues existed, then if they could potentially predict the likelihood of self-injury occurring and now specifically how these predictions can be formulated so that they are understood and can be practically utilized by the individuals in the child's life.

**Number three.** *Could the study of these physical cues provide development of a more comprehensive approach to re-directing self-injurious behaviour in the child informant?*

The findings were in fact during the research process developed into a comprehensive re-directive tool. In particular, the gestural coding system (see Appendix A, figure 1) and the tree of communication (see appendix A, figure 2) were specifically designed with the intention to assist in the re-direction of the self-injurious behaviour. This approach-coding the gestural observations and analyzing them, can potentially assist in the development of more effective movement programming. The design of both tools is basic and user-friendly. The individual would simply need to rely on his or her keen observations and ability to read what the child is communicating through his body. These tools have initiated the development of the bridge between movement and communication. The objective was to provide individuals outside of the trained professional eye to learn to comprehend the gestures and postures as a form of communication.

**Number four.** *How can the child informant's physical movement be engaged as a form of communication?*

The child's physical movement can be engaged as a form of communication if it is accepted and interpreted as one. Based on the descriptive history of his bodily expression, the child has always relied on his physical actions to communicate. The use of tools such as the gestural coding system can help engage his physical movement and translate its meaning to others who communicate via verbal language. Augmented by his continuous use of American Sign Language the intense need to self-injure could potentially be dramatically reduced. This in combination with access to physical activity opportunities that continue to expand his movement repertoire and his awareness of his own body can increase the quality of life of the child and individuals in his life. The implications these findings have on the future direction of research are other children who are for instance selectively mute, have challenges communicating through PECS, verbal language and sign language could potentially have a reliable mechanism to

communicate with. The individuals that have been deemed non-communicative could potentially have a world of communication opened to them.

### **Recommendations and Future Directions**

As I reflected with and through my research it became evident that two distinct areas needed to be acknowledged. In retrospect, interviewing the second parent would have added more depth to my case study. The father of the child-informant would have offered different insight. Additionally, interviewing the older sibling would have contributed to the depth of my research. All members of the family could have been interviewed. In hindsight, the first translating tool (the tree of communication) needed an additional feature to complete it: the environment. It would be necessary to locate the tree against the environment by further modifying it to include my refined tool. As I explored the recommendations for my research, I additionally suggested areas for future directions.

Based on the findings of this research project numerous directions for the future have been recognized. Further research on the relationship between physical activity and individuals with Autism needs to be conducted. Case studies such as this one need to explore issues and complexities that are rarely explored in research. Also, the two translating tools that were created during this research project need to be further developed, modified and then applied in this same adapted physical activity setting. Ideally, the tool's template will be standardized and disseminated as a common form utilized in the educational system and community at large. Future studies that identify gestural cues should be conducted to explore if precursors can be identified in populations outside of this case study because pre-cursors are most certainly unique to all individuals. Additionally, outside of the scope of Autism for instance other developmental disorders that have communicative challenges. The means to disseminate valuable information to the public; families and individuals living with disability need to be the focus of future research. The research community is isolated and excluded from the general public, the next steps are to find more practical means to unite and include individuals who are not deemed active members of research.

## APPENDIX A

This figure has been developed and informed by all three data sets: field observations, interviews and photo documents. The roots, core and branches are information that has been confirmed across all data sets. The possibility is to use this figure to help inform a comprehensive diagram complete with re-direct strategies specific to the branch of movement the self-injurious act appears to be following. It is important to note this translating tool is used in conjunction with both the gestural coding system and its details have been augmented by the photo documents of the child-informant as he interacted with the environment.

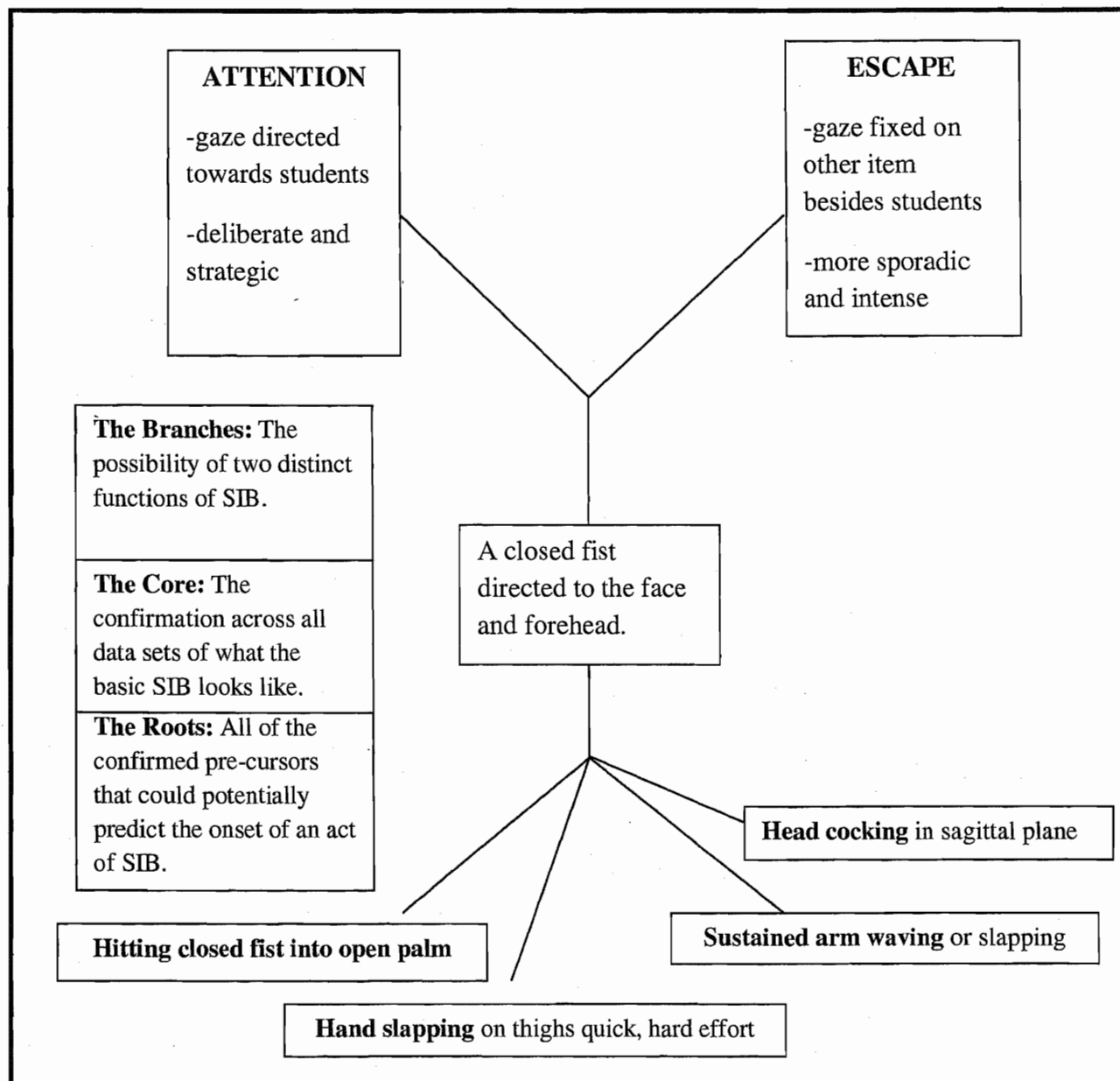


Figure 2. The Tree of Communication. A tool to help determine the form and function of SIB with the goal to predict the onset of an episode of SIB.

The image is of a person of neutral sex and is relative to the size of the child. The body is in anatomical position with the arms and legs pointing outwards laterally away from the body. The arms and hands are supinated with the palms facing forwards in the frontal plane. This is the standard position of reference in movement theory. The coding system was developed based on basic shapes, shades of black and white, and Laban's movement theory specifically the principle of effort. The coding grid is as follows: dark gray (movement cues warning higher likelihood of self-injurious episode), black (movement cues with highest likelihood of self-injurious episode occurring), light gray (movement cues with least likelihood of self-injurious episode occurring). The projected result of using this coding system is once tracked and coded to place a string of bodies next to one another and to visually inspect patterns that may otherwise become difficult when data is analyzed descriptively. The design of this coding system was influenced by the traditional forms used to document work place injuries. If generic body images are an effective means to track work place injury what not generalize its use to self-injuries? Training on how to use this coding system would be minimal and since it has been inspired by workplace injury document forms the majority of individuals working with children with Autism will have seen and received training on how to fill out similar forms at their workplace. Even though this particular generic coding system only presents the frontal portion of the body, the dorsal portion of the body would be available for use. This specific coding system was specifically designed to cater the topography of the child-informant's self-injury and he only engaged in self-injurious behaviour on the front of his body.

**Legend Ex: Closed left fist, hard effort, site of impact two on left temple/orbital bone.**

**'x'=location of SIB**

1:21 PM

-----=light effort (dotted line)

\_\_\_=medium to hard effort (solid line)

**'o'=positioning of hand**

○=open palm

●=closed fist

●=loose fist

**'□'=external object**

□=light weight, light effort

■=light weight, hard effort

■=heavy weight, hard effort

■=heavy weight, light effort

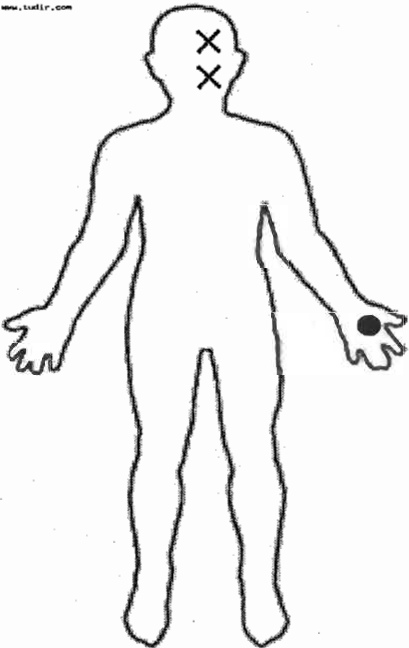
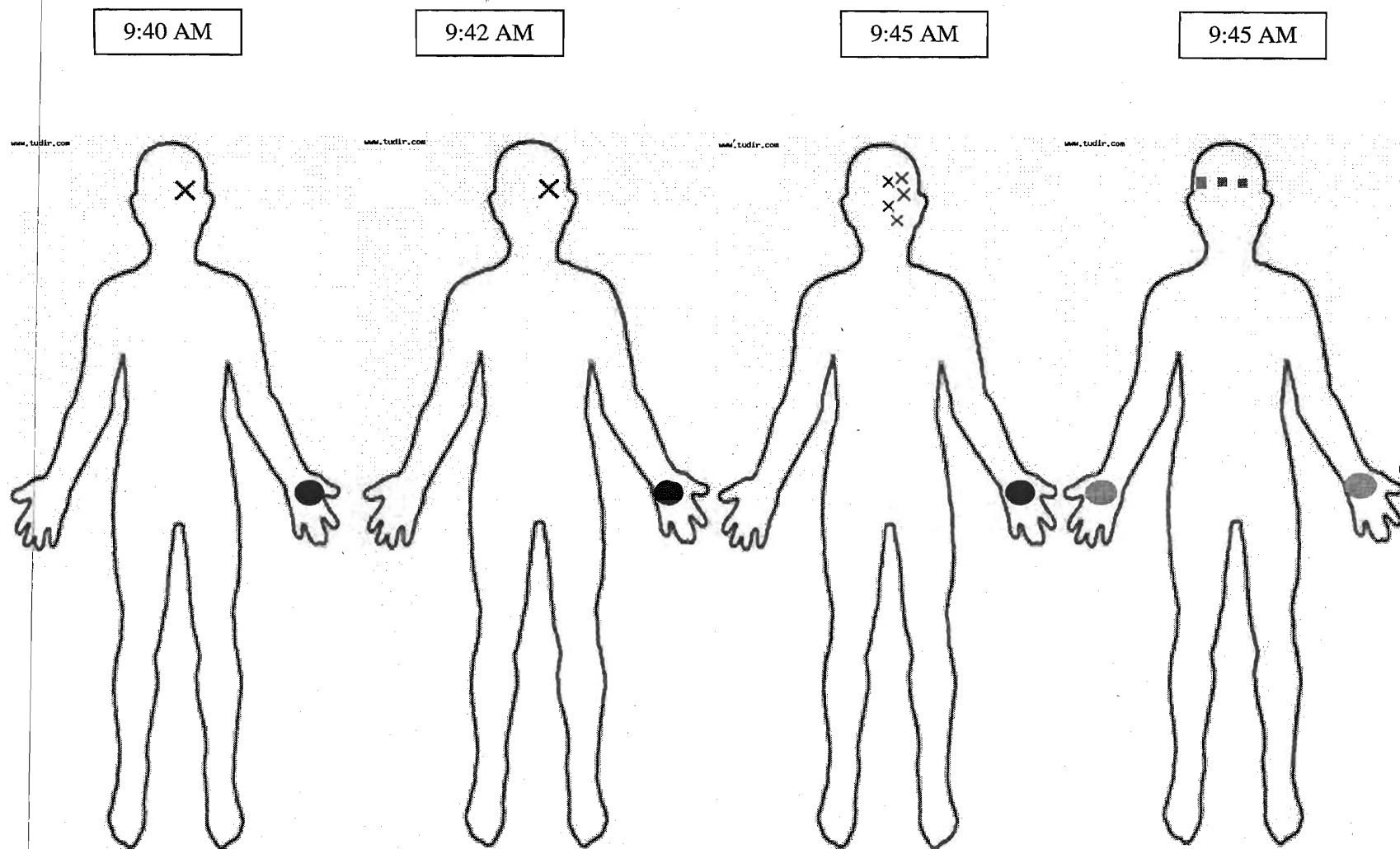


Figure 3. The Gestural Coding System Template. The objective is for the individual taking data to utilize this tool accompanied by a legend of codes to track the site and time of self-injury in addition to the effort used during the self-injurious episode.



*Environment:* field observations and photo documents indicate that on the fourth day of Movement Camp between the times of 9:40 am and 9:45 am the child-informant was participating in Games Skills (gross-motor movements) in the large gymnasium.

*Figure 4.* The Gestural Coding System Application. This is an example of the raw data informed by the child-informant's self-injury at Movement Camp-the coding has been applied, and the string of bodies is presented.

The development of the questions was influenced by current literature and background knowledge of the phenomenon. The organization and preparation of questions assisted in the collection of information rich data. This specific template was designed for the mother of the child, two others were modified specifically to seek information from both the student volunteer and the service worker.

### *General*

- Describe your relationship with the child?
- On a daily basis, how often do you observe the child's behavior?
- Are there any other people in your child's life that would be able to authentically describe your child's behaviour?

### *Physical*

- What are your child's favorite activities/things to do?
- How would you describe your child's movement?
- Why do you continue to enroll your child in the annual Movement Camp at Brock University?
- With your child in mind, what would you describe as 'meaningful physical activity'?
- What movement goals do you and your child have for this year?

### *Behavioural*

- Does your child engage in any stereotypic behaviour?
- If yes:
  - What would you call your child's stereotypic behavior?
  - Suppose I had never seen your child's repetitive behavior, describe to me what your child's repetitive behavior looks like.
  - How frequently does your child engage in stereotypic behaviour? (possibly expressed as percentage of day)
  - For what duration does your child engage in stereotypic behaviour? (possibly expressed in hours per day)
- Can you ever predict or do you ever know when your child will engage in stereotypic behavior prior to his engagement in it?
- If yes:
  - How are your predictions of stereotypic behaviour confirmed?
  - How do you believe you predicted the occurrence of the stereotypic behaviour?
- Tell me about your most common emotional response to your child's stereotypic behavior.

### *Social*

- How do you believe your child's stereotypic behavior affects his life? Your life? Your family's life?
- Do you believe by reducing your child's stereotypic behavior that his quality of life will increase?
- What current methods, supports or techniques are you and your child using, if any, to help redirect his stereotypic behaviour?



- Generally speaking, how well do you think people understand stereotypic behaviour?
- How well do you think the network of people in your child's and your life, understand stereotypic behaviour? (such as teachers, neighbors, friends)
- Previously, I remember you describing a specific incident that occurred at school, specifically on the school bus. Can you describe this incident to me?

*Figure 5.* Interview Guide. This guide was a series of prepared questions organized into four specific categories of interest: physical, social, behavioral and general.

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### References

- Barrera, F., Violo, R., & Graver, E. (2007). On the form and function of severe self-injurious behaviour. *Behavioural Interventions*, 22(1), 5-33.
- Beals, K. (2004). Early intervention in Deafness and Autism: One family's experiences, reflections and recommendations. *Infants and Young Children*, 17(4), 284-290.
- Block, M. & Rizzo, T. (1995). Attitudes and attributes of physical educators associated with teaching individuals with severe and profound disabilities. *Journal of the Association for Persons with Severe Handicaps*, 20(1), 80-87.
- Brownlow, S., Dixon, A. (1997). Perception of movement and dancer characteristics from point-light displays of dance. *Psychological Record*, 47(3), 1-11.
- Campbell, Gilmore & Cuskelly. (2003). Changing student teachers' attitudes towards disability and inclusion. *Journal of Intellectual & Developmental Disability*, 28(4), 369-379.
- Camurri, A., Lagerlof, I. & Volpe, G. (2003). Recognizing emotion from dance movement: Comparison of spectator recognition and automated techniques. *International Journal of Human-Computer Studies*, 213-225.
- Camurri, A., Mazzarino, B. & Volpe, G. (2004). Expressive interfaces. *Cognition, Technology & Work*, 6, 15-22.
- Carr E. G. & Durand V. M. (1985) Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis*, 18, 111-26.
- Connolly, M. (2008). The remarkable logic of Autism: Developing and describing an embedded curriculum based in semiotic phenomenology. *Sport, Ethics and Philosophy*, 2(2), 234-256.
- Creswell, J. (2007). Qualitative inquiry & research design: Choosing among five approaches. Sage Publications: Thousand Oaks.
- Diaz-Castroverde, F. (2009). Gesture description formats: Human computer interaction [PowerPoint slides]. Retrieved from [http://www.dtic.upf.edu/njblat/material/hci/students09/topics/HCI\\_TOPICS\\_major\\_Francisco\\_Garcia\\_Presentation.pdf](http://www.dtic.upf.edu/njblat/material/hci/students09/topics/HCI_TOPICS_major_Francisco_Garcia_Presentation.pdf)
- Duncan, M. (2001). The sociology of ability and disability in physical activity. *Sociology of Sport Journal*, (18), 1-4.
- Fee, V. E., & Matson, J. L. (1992). Definition, classification, and taxonomy. In J. K. Luiselli, J. L. Matson, & N. N. Singh (Eds.), *Self-injurious behavior: Analysis, assessment, and treatment* (pp. 3 - 20). New York: Springer-Verlag.
- Favazza, A., & Conterio, K. (1989). Female habitual self-mutilators. *Acta Psychiatrica Scandinavica*, 79, 283-289.

- Favazza, A. (1998). The coming of age of self-mutilation. *The Journal of Nervous & Mental Disease*, 186(5), 259-268.
- Generic Body Image. Outline of human body for kids. Retrieved from <http://www.tudir.com/?clc=vir.htm>
- Giangreco, Dennis, Cloninger, Edelman & Schattman. (1993). "I've counted Jon": Transformational experiences of teachers educating students with disabilities. *Exceptional Children*, 59(4), 359-372.
- Goodwin, D. & Watkinson, J. (2000). Inclusive physical education from the perspective of students with physical disabilities. *Adapted Physical Activity Quarterly*, 17, 144-160.
- Greenspan S. & Wieder S. (1999). A functional developmental approach to autism spectrum disorders. *The Association for Persons with Severe Handicaps*, 24, 147-161.
- Guardino, C. (2008). Identification and placement for Deaf students with multiple disabilities: Choosing the path less followed. *American Annals of the Deaf*, 153(1), 55-64.
- Guralnick, M. (2011). Why early intervention works: A systems perspective. *Infants and Young Children*, 24(1), 6-28.
- Hanley, G. , Iwata, B. & McCord, B. (2003). Functional analysis of problem behavior: A review. *Journal of Applied Behavior Analysis*, 36(2), 147-185.
- Handleman & S. L. Harris), pp. 95-133. Pro-Ed, Austin, TX.Schroeder, S. R., Mulick, J. A., & Rojahn, J. (1980). The definition, taxonomy, epidemiology and ecology of self-injurious behavior. *Journal of Autism and Developmental Disorders*, 10, 417-432.
- Hastings & Oakford. (2003). Student teachers' attitudes towards the inclusion of children with special needs. *Educational Psychology*,23(1), 87-94.
- Hodge, S. & Jansma, P. (2000). Physical Education majors' attitudes toward teaching students with disabilities. *Teacher Education and Special Education: The Journal of the Teacher Education Division of the Council for Exceptional Children*, 23(3), 211-224.
- Iwata, B., Dorsey, M., Slifer, K., Bauman, K., & Richman, G. (1994). Toward a functional analysis of self-Injury. *Journal of Applied Behaviour Analysis*, (27), 197-209.
- June, R., Rapin, I. & Tuchman, R. (1991). Hearing-impaired Autistic children. *Developmental Medicine and Child Neurology*, 33, 1062-1072.
- Kahng, S. Iwata, B. & Lewin, A. (2002). Behavioural treatment of Self-Injury, 1964 to 2000. *American Journal on Mental Retardation*, 107(3), 212-221.
- Lovaas O. I. & Simmons J. Q. (1969). Manipulation of self-destruction in three retarded children. *Journal of Applied Behavior Analysis*. 2,143-57.

- Lesniak, R. (2008). Self-injury behaviour: How can nurses HELP? *Journal of Christian Nursing*, 25(4), 186-193.
- Lewis, M., & Bodfish, J. (1998). Repetitive behaviour disorders in Autism. *Mental Retardation and Developmental Disabilities*, (4), 80-89.
- Lohrmann, S. & Bambara, L. (2006). Elementary education teachers' beliefs about essential supports needed to successfully include students with Developmental Disabilities who engage in challenging behaviors. *Research and Practice for Persons with Severe Disabilities*, 31(2), 157-173.
- Lourie R. S. (1949). The role of rhythmic patterns in childhood. *American Journal of Psychiatry*, 105, 653-60.
- Lovaas O. I. & Simmons J. Q. (1969). Manipulation of self-destruction in three retarded children. *Journal of Applied Behavior Analysis*. 2,143-57.
- Machoiian, L. (2001). Cutting voices: Self-injury in three adolescent girls. *Journal of Psychosocial Nursing*, 39(11), 22-29.
- Malandraki, G. & Okalidou, A. (2007). The application of PECS in a Deaf child with Autism: A case study. *Focus on Autism and Other Developmental Disabilities*, 22(1), 23-32.
- Maletic, V. (1987). Body, space, expression: The development of Rudolf Laban's movement and dance concepts. Berlin: Walter de Gruyter & Co.
- Mangnail, J., & Yurkovich, E. (2008). A literature review of deliberate self-harm. *Perspectives in Psychiatric Care*, 44(3), 175-184.
- March, J.S. & Mulle, K. (1998). *OCD in children and adolescents: A cognitive-behavioural treatment manual*. New York, NY: The Guilford Press.
- McCord,B., Thomson, R. & Iwata, B. (2001). Functional analysis and treatment of self-injury associated with transitions. *Journal of Applied Behavior Analysis*, 34(2), 195-210.
- Merriam, S. (1995). What can you tell from an N of 1?: Issues of validity and reliability in qualitative research. *Journal of Lifelong Learning*, (4), 51-60.
- Muehlenkamp, J. (2005). Self-injurious behaviour as a separate clinical syndrome. *American Journal of Orthopsychiatry*, 75(2), 324-333.
- Murphy, G., Hall, S., Oliver, C. & Kissi-Debra, R. (1999). Identification of early self-injurious behaviour in young children with intellectual disability. *Journal of Intellectual Disability Research*, 43(2), 149-163.
- Murphy, N. & Carbone, P. (2008). Promoting the participation of children with disabilities in sport, recreation and physical activities. *American Academy of Pediatrics*, 121, 1057-1061.
- Nolen-Hoeksema, S. (2008). *Abnormal Psychology*. McGraw-Hill: New York, NY.

- Pan, C. & Frey, G. (2006). Physical activity patterns in youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 36, 597-606.
- Patton, M. (2002). Qualitative research & evaluation methods. Sage Publications: Thousand Oaks.
- Potter, N. (2003). Commodity/body/sign: Borderline personality disorder and the signification of self-injurious behaviour [Electronic version]. *Philosophy, Psychiatry and Psychology*, 10(1), 1.
- Richman, D. (2008). Early intervention and prevention of self-injurious behaviour exhibited by young children with developmental disabilities. *Journal of Intellectual Disability Research*, 52(1), 3-17.
- Rogers S. J., Hall T., Osaki D., Reaven J. & Herbison J. (2000).The Denver model: a comprehensive, integrated educational approach to young children with autism and their families. In: *Preschool Education Programs for Children with Autism*, 2nd edn (eds. J. S.)
- Roper, L., Arnold, P. & Monterio, B. (2003). Co-occurrence of Autism and Deafness: Diagnostic considerations. *Autism*, 7, 245-253.
- Rosenhall, U., Nordin, V., Sandstrum, M. Ahlsen, G. & Gilberg, C. (1999). Autism and hearing loss. *Journal of Autism and Developmental Disorders*, 29(5), 349-357.
- Schroeder, S. R., Mulick, J. A., & Rojahn, J. (1980). The definition, taxonomy, epidemiology and ecology of self-injurious behavior. *Journal of Autism and Developmental Disorders*, 10, 417-432.
- Schwartz, P. (1995). Laban movement analysis: Theory and application. *Journal of Physical Education, Recreation and Dance*, 66(2), 25-26.
- Symons, F. & Thompson, T. (1997). Self-injurious behaviour and body site preference. *Journal of Intellectual Disability Research*, 41(6), 456-468.
- Symons, F., Sperry, L., Dropik, P., & Bodfish, J. (2005). The early development of stereotypy and self-injury: a review of research methods. *Journal of Intellectual Disability Research*, 49(2), 144-158.
- Symons, F., Butler, M., Sanders, Feurer, I., & Thompson. T. (1999). Self-injurious behaviour and Prader-Willi Syndrome: Behavioural forms and body locations. *American Journal on Mental Retardation*, 104(3), 260-269.
- Sears, L., Vest, C., Mohamed, S., Bailey, J. Ranson, B., & Piven, J. (1999). An MRI study of the Basal Ganglia in Autism. *Prog. Neuro-Psychopharmacology & Biology Psychiatry*, (23), 613-624.

- Shentoub S. A. & Soulairac A. (1961) L'enfant automutilateur: les conduites automutilatrices dans l'ensemble du comportement psychomoteur normal. Etude de 300 cas. *Psychiatrie de l'Enfant* 3, 405-524.(reported in Green A. H. (1967) *Archives of General Psychiatry* 17, 234-244).
- Vernon, M. & Rhodes, A. (2009). Deafness and Autism Spectrum Disorders. *American Annals of the Deaf*, 154(1), 5-14.
- Warren S. F. & Yoder P. J. (1997). Communication, language, and mental retardation. In: *Mental Retardation* (ed. W. MacLean), pp. 379-403. Lawrence Erlbaum Associates, Mahwah.
- Wendell, S.(1996). The rejected body: Feminist philosophical reflections on disability. Routledge: New York.
- Zlotnick, C., Shea, T. Pearlstein, T., Simpson, E., Costello, E., & Begin, A. (1996). The relationship between dissociative symptoms, Alexithymia, impulsivity, sexual abuse, and self-mutilation. *Comprehensive Psychiatry*, 37(1), 12-16.